

Italy and the COVID-19 long-term care situation

Sara Berloto, Elisabetta Notarnicola, Eleonora Perobelli, Andrea Rotolo

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Author

Sara Berloto, Observatory on Long Term Care, Cergas SDA Bocconi School of Management.

Elisabetta Notarnicola, Observatory on Long Term Care, Cergas SDA Bocconi School of Management.

Eleonora Perobelli, Observatory on Long Term Care, Cergas SDA Bocconi School of Management.

Andrea Rotolo, Observatory on Long Term Care, Cergas SDA Bocconi School of Management.

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

Impact of the COVID19 outbreak so far and population level measures Number of positive cases in population and deaths

As of July, 31st the official total number of positive cases in Italy is 247,158 and the number of deaths reached 35,132. A total of 199,796 people have currently recovered from the virus, and 47 are hospitalized in intensive care¹. On the same day, 61,858 new tests have been performed: within this sample the ratio between newly positive cases over the total daily performed tests resulted to be equal to 0.6% (1 case every 161 tests)².

The most affected region is by far Lombardy: since the start of the epidemic 96,142 cases (deaths and recovered included) have been registered, followed by the regions of Piedmont and Emilia-Romagna, respectively with 31,646 and 29,634 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 22nd of July: the average age of decease is 80 years old although the median age is 82 years old (20 years higher compared to the average age of infected people, which is 62 years

¹ Dipartimento della Protezione Civile:

http://opendatadpc.maps.arcgis.com/apps/opsdashboard/index.html#/b0c68bce2cce478eaac82fe38d4138b1

2https://lab.gedidigital.it/gedi-visual/2020/coronavirus-i-contagi-in-italia/?ref=RHPPRB-BS-I254751933-C4-P1-S1.4-F4&refresh_ce

old). Deceased people are mostly men (57,6% of the total) and in 61,8% of cases were presenting three or more pre-existing chronic pathologies³.

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 21st 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 31st of January.⁴ 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 regulations⁵ 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 epidemiological emergency. At the end of February the first cases and deceased 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 22rd carnival celebrations and some soccer matches were cancelled.

On 1st of March, a Ministerial Decree⁶ established that the Italian national territory was divided in three areas: (i) Red zones (composed of Northern Italy municipalities that registered a certain level of COVID-19 cases 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 still had the liberty of limited 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 decree⁷ 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 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 expended several times until the 3rd May.

If containment measures and lockdown were enforced by the central government, the same cannot be said for provisions detailing how the health sector and the LTC should respond 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 previous years, same months⁸. The ISS carried out a dedicated survey to

³ Last official data available on Epicentro ISS dashboard. Available at: https://www.epicentro.iss.it/coronavirus/bollettino/Report-COVID-2019_22_luglio.pdf

⁴http://www.salute.gov.it/portale/nuovocoronavirus/dettaglioNotizieNuovoCoronavirus.jsp?lingua=italiano&menu=notizie &p=dalministero&id=4035

 $^{^{5}\} https://www.gazzettaufficiale.it/eli/gu/2020/02/23/45/sg/pdf$

⁶ https://www.gazzettaufficiale.it/eli/id/2020/03/01/20A01381/sg

⁷ https://www.gazzettaufficiale.it/eli/id/2020/03/08/20A01522/sg

⁸ See for example:

⁻ https://www.giornaledibrescia.it/storie/coronavirus-il-punto/indagine-sulle-rsa-i-morti-per-influenza-15-volte-i-COVID-1.3471180

collect evidence on this⁹, which was sent to 3,292 nursing homes out of the 4,629 operating on the national territory. 1,356 nursing homes (41,2% of the targeted) responded and reported an overall mortality of 9,1% betwee February 1st and May 5th. Among the 9,154 total deaths, only 680 were officially tested positive, though 3,092 more had flu and COVID-19-related symptoms. The ISS affirms that these two numbers should be analysed jointly, accounting for 41% of the deaths (3,772/9,154) of the period as COVID-19 related. These first figures are close to those reported by nursing homes managing directors, which shocked the public opinion¹⁰.

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-19¹¹. 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 among 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 was 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 the LTC sector was not conceived and developed as a comprehensive model, rather it emerged from multiple legislative interventions that aimed intermittently at integrating what existed already (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.

With regards the supply of public in-kind services in the country, in 2016 (latest data available), there were 285.686 places 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 the Trentino Alto-Adige Region, there are 25 beds per 100 not-self-sufficient people aged over 75 (who represent the share of the population that could

https://www.ansa.it/trentino/notizie/2020/04/03/coronavirus-altri-17-morti-in-trentino-204-nuovicontagi_bd98b1e0-e10b-4830-92a9-b7ef4840aa25.html

https://it.reuters.com/article/idITKBN2161IV

⁹ https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf

¹⁰ See footnote **Error! Bookmark not defined.**

¹¹ 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

most likely access nursing homes); in Basilicata there are 0.65, signalling the almost total absence of services in some areas of the country. 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 older people who were not self-sufficient) and on the number of users of public services one estimate the public services LTC coverage rate, which, in 2016, was equal to 37%. This means that the LTC system is only supporting to one out of three persons in need. Moreover, considering that most part of the home care coverage consists of an average of 16 hours of care per year, it is fair to say that the public welfare system is far from covering and answering to the needs of older people who need care and their families.

On top of this, the 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 public spending in this sector. The two-thirds of older people who do not make it to the public welfare system seek alternatives to answer their needs, there are mainly five possible different options, 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 or undermining their savings, trying to set up a 24/7 cycle of care (it is estimated that there are 1,005,303 such workers in Italy (Berloto and Perobelli, 2019));
- 5. The older persons 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 Personal Protection Equipment (PPE) in healthcare and LTC settings¹². 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 training of care workers and suggesting extensive testing.

Much of the legislation was promoted from the Regions, since they represent the institutional level in charge of defining the operating rules and guidelines for the LTC sector. During the pandemic, Regions

¹²

http://www.trovanorme.salute.gov.it/norme/renderNormsanPdf?anno=2020&codLeg=73694&parte=1%20&serie=null

(and local health authorities) gave directions, regulations and instructions to the health institutions for older people, for the management of COVID-19 cases and their containment and prevention. The spread of the virus in the sector was very vast as witnessed by previously exposed data: it had a significant impact on all settings providing care to a population particularly at risk. The combination of these two factors has led to the need to define emergency and risk management plans which had to be differentiated between the LTC sector and the "rest of the world", precisely to take into account these specificities and, in some cases, guarantee additional protection to the older population. The healthcare sector managers, for their part, have activated internal risk management strategies, aimed at protecting their structures and ensuring the maximum quality of assistance. At the same time, however, common regional instructions were also needed to coordinate action in the LTC domain, also guaranteeing homogeneous treatment consistent with the simultaneous "pure health" policies that were implemented.

At different times and intensity, the Regions adopted LTC guidelines that were issued both with reference to the first emergency phase (thus providing the first instructions and measures addressed to the management of services), and for the subsequent phases, regulating the screening and health treatment policies up to the re-opening of the health facilities. In this report we present the results from an analysis of all the measures, instructions, rules etc. adopted in nine different Italian regions during the pandemic. Evidence shows that:

- During the different phases of the emergency, and in particular during the first emergency
 phase, Regions took action in the LTC domain at very different times and with a general
 misalignment with respect to the rapidity and extent of the spread of the pandemic;
- The various regional entities have issued very different instructions on how to proceed in the management of LTC facilities during an emergency, both in terms of methods and extension of the guidelines provided.

This analysis provides important elements on (i) the crisis management models implemented in the various contexts, which is useful to reflect on the management of the COVID-19 emergency, and (ii) the LTC sector as a whole. Our approach takes up indeed some typical characteristics of the sector which have been emphasized even more in the emergency situation of the pandemic, namely: the fragmentation of the social and healthcare system, the critical issues in coordinating with the entire health network, the questioning of the vocation of the services existing today and the lack of attention to the resources of the sector. These four critical elements sharply emerged from the analysis of regional policies, and they open the field even further to the discussion on how to gear up in order to overcome them in the near future.

Analysis of COVID-19-related regional policies: methods

The analysis conducted is based on the investigation of the measures put in place by nine Italian regions in the period between the 22nd of February and the 3rd of June 2020 in terms of guidelines, ordinances, regulations and indications prepared with specific reference to the LTC sector and in particular to the management of COVID-19 in residential facilities for older people. The analysis focused on a selection of nine regions (Lombardy, Piedmont, Emilia-Romagna, Veneto, Trento, Liguria, Tuscany, Marche, Lazio). The choice of the Regions to be analyzed was made through a twofold criterion:

 Regions that registered over 5,000 COVID-19 diagnosed cases as of June 15th (source: Italian National Institute of Health), so to select territorial contexts where the pandemic was most intense and widespread; 2. Regions with a greater diffusion of LTC facilities for older people (see Berloto et al. In the OASI 2019 Report).

For the nine Regions identified, all the measures adopted from the end of February 2020 were reviewed, then classified and analyzed according to five distinct dimensions:

- 1. **Measures for the management of services**, analyzing all that concerned the COVID-19 management inside nursing homes;
- Measures addressed both to the health and LTC sector, to consider whether and how the methods of coordination between the hospital, regional and LTC network have been set up within COVID-19:
- 3. **Measures for the management of patients and positive cases**, with particular reference to methods of screening and identification of suspected cases, security measures in the structures, management of new accesses, resignations, (screening, accesses, etc.);
- 4. **Measures addressed to the personnel of the social and healthcare sector**, with respect to the management of suspicious and certain cases of COVID-19 but also regarding training, procedures and protocols adopted for the safety of all the staff of the structures, etc.;
- 5. **Measures adopted to revise services' features**, to check whether, for example, the welfare standards, the pricing procedures, etc. were revised in the reference period.

On which elements of the sector have the regional policy interventions focused during the early phase of the pandemic?

The period defined as Phase 1 goes from February 22nd, the day after the first outbreak in Lombardy, to May 4th, the day national lockdown was over. This phase was characterized by the focus of the regional legislator on the containment of the emergency, which emerged, exploded and was managed in that period. It is important to point out that in all the regional contexts analyzed, the first measures specifically referring to the LTC and to facilities for older people (or in any case the first guidelines which contemplated expressing indications for this sector) were produced starting from mid-March, with a time difference of three weeks compared to the first initiatives launched in the health sector. This is relevant to the effectiveness of subsequent measures and to the importance that has been attributed to the the social and healthcare sector from the very beginning of the crisis. This temporal dynamic is emblematic: the initial priority but also the attention of the ongoing management of the emergency was catalyzed by the healthcare sector, whilst the issue of coordination with the LTC network did not arise at all or was delayed over time.

Table 1 shows a summary of this investigation. Below, we comment on the trends and dynamics common to the various Regions for each dimension of analysis after presenting a synthetic synoptic picture.

Table 1. Covid-19 Regional response in Phase 1 (February – May 2020)

| Phase 1 | | | | | | | | |
|-----------|---|---|--|--|---|--|--|--|
| | Measures for the management of services | Measures addressed both to the health and LTC sector | Measures for the management of patients and positive cases | Measures addressed to the personnel of the LTC sector | Measures adopted to revise services' features | | | |
| Lazio | ✓ | | ✓ | ✓ | | | | |
| Liguria | ✓ | | ✓ | ✓ | | | | |
| Lombary | ✓ | | ✓ | ✓ | | | | |
| Marche | ✓ | | | | | | | |
| PA Trento | ✓ | | | | | | | |

| Piedmont | ✓ | ✓ | ✓ | |
|----------------|---|---|---|--|
| Emilia-Romagna | ✓ | ✓ | ✓ | |
| Tuscany | ✓ | ✓ | ✓ | |
| Veneto | ✓ | ✓ | ✓ | |

With respect to the measures for the management of services, analyzing all that concerned the management of the COVID-19 emergency within the residential care settings for older people, Regions were mainly oriented to order the closure of the services (both in terms of cessation of activities and of physical limitation of access) by regulating the methods of access. The focus was on the "physical" containment of existing situations and on the prevention of new outbreaks, giving indications on the obligations of use of personal protective equipment (PPE) and on the safety procedures to follow. However, this was done by indicating mandatory standards and constraints, but paying little attention to the operational and managerial methods of implementation. An exception is that of the Marche Region, which has provided checklists and operational guidelines designed specifically for the care facilities. Again, with respect to the operational theme, it is interesting to note how some Regions (for example Liguria and Tuscany) have activated task forces or operational units dedicated to the management of COVID-19 cases in continuity between the social and healthcare network and other services, in order to oversee what occurred in each structure. In some regions (Lazio, Lombardy, Piedmont), structural and operational requirements have also been envisaged for the creation of Covid centers or centers for the management of symptomatic or infected guests. With respect to home care, there were opposite attitudes with Regions that blocked the services and the access to people's homes, and others that instead incentivized them.

With respect to the *coordination measures* between the health and socio-healthcare sector, an analysis was made of whether and how integration methods were established between the hospital, regional and social-health network in the context of the COVID-19 emergency. On this, no Region among those analyzed has adopted measures specifically aimed at this objective. Even in the cases mentioned above, Liguria and Tuscany, the operational units responsible for coordination between settings had the primary objective of evaluating and managing individual cases and not the organizational supervision of the network as a whole. The topic was delegated to the local level, in the direct relationship between healthcare institutions and care homes which, on the basis of highly differentiated indications, also the result of historical relationships and dynamics, gave themselves operating methods and rules. The management of the patient/user relationships and professionals flows between the network nodes has in some cases been hampered if not blocked, for example with the prohibition of transfer to the emergency room or hospitals. The objective pursued was therefore opposite: instead of reinforcing coordination between settings, the aim was to isolate them and make them independent.

With respect to the measures for the *management of patients and positive cases*, with particular reference to the methods of screening and identification of suspect cases, security measures in the structure, management of new accesses, resignations, (screening, accesses etc.) there is a homogeneity among the actions undertaken by the individual Regions. The first measures were oriented towards blocking new entrances; subsequently (and not always promptly) steps were taken to provide guidelines and recommendations for identifying COVID-19 cases and securing the other guests in the facility; only in the last instance, in the contexts in which accesses for specific situations have been reopened, triage and user profiling mechanisms were also introduced. The start of screening procedures and access to swabs as a preventive practice started only at the end of Phase 1. Among all, the Tuscany case is interesting because dedicated information flows have been

implemented, precisely regulating the times and ways with which to act in the presence of a suspected case.

With respect to the *measures addressed to staff in the LTC sector*, it is noted that Regions have mainly focused on giving very operational and peremptory indications on the use of PPE without giving space to training and emergency management preparation practices. Compared to this, there is a variability between more general indications provided to the staff of the structure (e.g. Piedmont) and cases in which the indications have been provided in detail for the individual professional figures (e.g. Tuscany). Once again, the issue of training of care workers and not of care homes has been delegated to the local level and managed by each structure or in conjunction with the healthcare companies. Also in this case, the attention went on the issues of isolation and containment of cases both by limiting movement and through the use of devices, without however paying attention to what the staff of the facilities could and should have done during the emergency or to any greater or different need for staff.

With respect to any *measures to revise services' features* (welfare standards, pricing methods, etc.), no initiative has been registered by the Regions investigated. During Phase 1, the structures were left to the standard rules pre-COVID-19 and the need to review and adapt them to the changed and extraordinary context was not considered. If, on one hand, this may have been necessary in the initial expansion phase of the emergency, given the uncertainty and the need to focus first to other measures, on the other hand, when the epidemic peaked, it was unrealistic to think that care facilities could operate "normally" according to the usual standards. Despite this, the pricing methods and the required standards have not been changed. We point out that the Tuscany Region, which officially suspended the administrative and quality controls for the whole period, was the only one to have promoted a Regional provision in this sense.

The most critical issues appear to be related to the coordination with the healthcare system, the questioning of the vocation of the services that exist today and the lack of attention to the allocation of resources in the sector. Moreover, what happened in Phase 1 and what was promoted by the Regions help to reinforce their relevance. In terms of fragmentation, it can be said that in the early COVID-19 period this characteristic was extreme: nursing homes were completely isolated from a physical point of view (by virtue of the containment of the epidemic) but also with respect to the access to the information and support that could come from the network of health and social and health services. The various nodes of the health sector found themselves operating in full solitude without attempts to coordinate them being institutionalized or formalized. The resources dedicated to the sector have been scarce (see for example PPE and personnel) and no support investments have been foreseen. The mission of the services, already critical, has been further extreme: some nursing homes have found themselves operating as real COVID-19 hospitals, having to manage numerous cases within them, but without being able to rely on medical care or on the support of hospitals or specialized centers.

Regional measures in Phase 2: which main aspects have been addressed to manage the LTC recovery?

During the so-called Phase 2 (from the 4th of May to the 3rd of June) the attention shifted from the necessity to overcome the emergency peak to the identification of (safety) mechanisms to gradually return to the pre-COVID-19 pattern of services. This change occurred also with reference to the LTC sector: in order to capture the most significant measures adopted in different regional contexts, an additional investigation has been conducted to analyze what happened in the same nine Regions already discussed in Phase 1.

After a few months (from late March – April) in which the Covid-19 theme has progressively become more and more connected to the elderly and LTC sector, it was expected that in the transition towards Phase 2 this attention would be kept constant in order to extensively plan the recovery and to plan re-opening of different facilities. On the contrary, several regional indications were again showing the same pattern that has been observed in the previous phase of the COVID-19 epidemic (see **Table 2**).

Table 2. Covid-19 Regional response in Phase 2 (May 2020)

| Phase 2 | | | | | | |
|----------------|---|---|--|--|---|--|
| | Measures for the management of services | Measures addressed both to the health and LTC sector | Measures for the management of patients and positive cases | Measures addressed to the personnel of the LTC sector | Measures adopted to revise services' features | |
| Lazio | | | √ | ✓ | ✓ | |
| Liguria | | | ✓ | ✓ | ✓ | |
| Lombardy | ✓ | | | | | |
| Marche | ✓ | | ✓ | ✓ | ✓ | |
| PA Trento | ✓ | | √ | √ | | |
| Piedmont | √ | | ✓ | ✓ | | |
| Emilia-Romagna | √ | | √ | √ | ✓ | |
| Tuscany | √ | | √ | | | |
| Veneto | √ | | √ | ✓ | | |

Compared to the measures for the management of COVID-19 in residential facilities, the main focus in Phase 2 has been on the restoration of the pre-COVID-19 "normal", hence dedicating regulations and indications for the re-opening of spaces and for allowing visits, as well as the control and prevention of emergence of new cases in care homes. This was managed by reviewing some structural requirements in terms of size (for example in Emilia-Romagna, small dedicated units have been set up) or by working on procedures for screening and swabs. During this period, the other network services (day care centers and homecare) were reopened. Interesting is the case of the Lazio region that started a process of revision of the models of taking charge not only for residential facilities, but also by combining other health and social services in the logic of promoting an integrated perspective of services for the elderly to better manage cases COVID-19.

Apart from the Lazio experience, no specific guidelines or indications were identified in Phase 2 with respect to the *coordination between the health and social and health sector*. Also, in this Phase 2 the theme was not put on the "legislative" agenda of the Regions and indications supported by structured initiatives and regulations were not produced. Rather, nursing homes have been kept separated without regulating common elements with other services.

With respect to the definition of *measures for the management of patients and positive cases* in the facilities, several Regions have aligned themselves with the reference standards provided by the Istituto Superiore di Sanità for the health care sector. With respect to the internal procedures to be started in the services, some Regions (Piedmont and Lombardy) have delegated the issue to the responsibility of the individual institutions and facilities, directly called to identify responsible ad hoc figures and to define their own processes. For examples, the Veneto Region indicated that each individual local health authority proceeded to assess the state of care homes in the area by identifying ad hoc criteria and procedures for the reopening to be managed in a progressive and differentiated way for each district.

With reference to *personnel measures*, there is a wide regional differentiation. A positive development has been that, unlike in Phase 1, more attention has been paid to personnel training on how to use

PPE etc., albeit with opposite trends. Some regions (Veneto, PA Trento for example) have provided specific indications regarding the training of socio-health personnel, equating it to health personnel and making content and number of hours mandatory. Others instead (such as Lombardy) have assigned responsibility for training to the individual facilities, providing in the second instance that healthcare institutions can become promoters of initiatives. In addition to training, numerous indications were given regarding the correct use of PPE and internal procedures for identifying suspect cases among staff, in continuity with Phase 1.

With respect to possible service review measures, for welfare standards, pricing methods, etc., there is only one Region that has actively promoted a structured initiative. The Emilia-Romagna region has provided for an extraordinary and temporary remuneration mechanism for all costs incurred from March 20 onwards for empty places and reduction in admissions. This guarantees that facilities and companies return part of the fixed costs incurred in an emergency period, in fact acting on the possibility of the facilities achieving economic balance despite the emergency. The Region plans to pay, in the absence of occupation of the place, the minimum assistance fee, guaranteeing a minimum remuneration.

Even in Phase 2, the critical features of the LTC sector (fragmentation of the socio-health system, criticality in coordination with the heath care system, questioning of the vocation of the services existing today and little attention to the allocation of resources in the sector) remained valid and no efforts have been made towards possible solutions or actions that could mitigate them. However, there have been some positive signs on specific issues, namely:

- The issue of coordination in the social and healthcare sector and within the healthcare network, touched by attempts to hypothesize ways of taking charge between care settings (as promoted by Lazio);
- The theme of programming services in a system logic and no longer of fragmentation with the Venetian attempt to manage the post-COVID-19 social and health network on the basis of territorial monitoring;
- The theme of sustainability and resources at stake promoted by Emilia-Romagna which introduced a correction to the financing system to support the sector.

4.2. Care coordination issues

One of the major problems with Italy's management of the COVID-19 crisis, 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 Hospital has been blocked, providing guidelines to treat even the most severe case without access to the 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 did not have neither appropriate staff nor equipment.

Concerning staff, transfer 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 to provide training and expertise. This happened following specific agreement between providers. At the same time, many providers reported that they have 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 care workers applied, attracted by public sector contractual conditions (generally better than contracts applied in private nursing homes).

4.3. Care homes

4.3.1. Prevention of COVID-19 infections

Prevention of COVID-19 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 13, only requiring residential services to suspend visitations (some nursing homes autonomously suspended external visits before this date). This implies that fragile older people have been exposed for at least three weeks to visitors, possibly positive and asymptomatic, with no restrictions nor instructions 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. 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 contested by both care providers and their representatives, due to the high risks that such exposition could represent for both workers and patients. For this reason, this measure was implemented in a very few occasions.

On April 26th, the Italian Government issued a new decree¹⁴ 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 lack of ability to track down and control the spread of the COVID-19 in nursing homes, failing in testing suspected cases among residents and care personnel. Even today, current procedures do not foresee testing residents in nursing homes, not even those presenting symptoms¹⁵. 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,

¹³ DPCM 14/2020. https://www.gazzettaufficiale.it/eli/id/2020/03/09/20A01558/sg. Disposizioni urgenti per il potenziamento del Servizio sanitario nazionale in relazione all'emergenza COVID-19

¹⁴ DPCM 26/04/2020 http://www.governo.it/sites/new.governo.it/files/DPCM 20200426.pdf

¹⁵ https://it.reuters.com/article/idITKBN2161IV

Marche and Piemonte) who were under pressure for the peak of COVID-19 patients, started to reject and deny admission for 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 cared for in facilities not equipped for high-severity conditions and lacking the specialized health care workers that you can find in other settings such has hospitals. Moreover, access to palliative care has been critical, not only for care homes residents. 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 patients¹⁶.

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 come workers. Italy faced an enormous shortage of masks, tests, gowns, which deeply affected the social care and healthcare personnel. New PPE supplies were primarily directed to hospitals and nursing homes were left struggling to find the adequate equipment to protect their workers and residents. 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 needs¹⁷. In the ISS survey, respondents stated that some of the major problems encountered during the crisis were related to the weak guidelines given to limit the spread of the disease, the lack of medical supplies, 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 facilities, resulting in an incredibly high number of infected residents and care personnel, together with high mortality.

4.4. Impact on unpaid carers and measures to support them

Informal caregiving has a great relevance in Italian Long-Term Care system. Prior to the COVID-19 emergency, researchers (Berloto and Perobelli, 2019) estimated that more than 8 million informal caregivers were involved in the assistance of family members, plus more than 1 million paid care workers among which nearly 60% had no professional contracts 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 (a high share are 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 persons they provide care to. Any form of compensation or support is foreseen at the national level for informal caregivers, with some regional exceptions.

The emergence of COVID-19 had an enormous impact on informal caregiving systems. Social distancing and lockdown measures based on municipalities and regional territories initially suspended any form of connections between people relying on care and caregivers from their families. After a first period, assistance to dependent family members was added among the exceptions allowing travelling from one place to the other. There are media reports that carers faced major problems to access shops so that they could obtain food and medication for the people they supported since no preferential access had been organized. As of the 30th of April, no specific measures at National or Regional level have been undertaken 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 job (i.e. being replaced by family members

¹⁶ https://www.fedcp.org/images/file/1113/comunicato-stampa-congiunto020420r.pdf

 $^{^{17}\,\}underline{\text{https://www.ecodibergamo.it/stories/bergamo-citta/carnevali-arrivate-mascherine-nella-notteaiuto-alle-strutture-andiamo-avanti}\ 1344722\ 11/\underline{}$

forced to remain at home by the lockdown, there are media reports that this happened in 30% of the cases) or continued moving between households to provide assistance without having any form of training or access to PPE, probably contributing to the spreading of COVID-19. Since many of them are irregular workers, 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 have been discussed.

4.5. Measures for people with disabilities

On March 17th the National Government established¹⁸ the closure of all day centres 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, so the final decision lays on the local health authority.

With regards home care, the same law established that local authorities shall try to guarantee interventions for those who were benefitting from the service, only in case they can guarantee adequate protection for both care workers and users. Caregivers might break the lockdown rules to visit people with disabilities only in case of necessity.

The National Office for People with Disabilities created a section on its website to answer to the FAQ related to COVID-19¹⁹. As concerns people with intellectual disabilities, the office signals that ANFASS (the National Association of People with intellectual and relational disabilities) drafted the guidelines for caregivers and family members on how to deal with the emergency and with stress.

As of April 30th the national measures to support caregivers are mainly related to flexible work arrangements. The National Association for People with disabilities (FISH) has called for stronger action to guide people with disabilities and their families in tackling the emergency, both in terms of provision of services and financial support.

4.6. Impact on people living with dementia and measures to support them

In Italy, people living with dementia are mainly 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 promoted at the local level. National Associations of patients reported that the COVID-19 crisis impacted on supporting people with dementia. The majority of day centres (both public and private) have been closed since 8th of March, and no alternative was provided. Equally, the home care activities available were cancelled. As of the 30th of April, no specific measures have been undertaken 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 for people living with dementia at home. Other associations promoted the starting of call centres dedicated to supporting caregivers.

¹⁸ http://www.handylex.org/stato/d170320.shtml#a47

¹⁹ http://disabilita.governo.it/it/notizie/nuovo-coronavirus-domande-frequenti-sulle-misure-per-le-persone-con-disabilita/