

Corona Diaries of Aging and Family Care in Italy

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Abstract This paper focuses on the experiences of home care for elderly people collected during the first phase of the pandemic in Emilia-Romagna, Italy. The Italian response to the virus has been fragmented so far, due to differences in the way the healthcare system is managed, according to regions and the regulations of individual local healthcare units. Emilia-Romagna is one of the wealthiest areas in terms of its welfare system and is associated with a long-standing tradition of a community-care approach targeted to the prevention of chronic health diseases. The pandemic also posed threats to regions such as Emilia-Romagna causing the interruption of semi-residential care services, community-based health programmes and support services to home care. The text uses daily-life fragments to show how a small, interconnected group dealt with family care for elderly people. By showing how the pandemic met with pre-existent fieldwork relationships, the article discusses the relationship between chronic diseases, forced isolation, and care activities. This text offers a broad understanding of the family care system, which includes also the care provided by home-care workers. The text shows how community acts of care and reciprocity played an important role in filling the gap left by institutions and public care services. The pandemic just worsened the already existing social inequalities in care, which cannot be masked by the rhetoric on active aging and family care. These ideas need a serious engagement with structural reforms and cannot be completely left to individual capacities or informal acts of communitarian values and reciprocity.

Keywords pandemic – social isolation – family care – active aging – community care – Italy

Introduction

In April 2020 I received a call from Maria¹, a home-care worker from Emilia-Romagna (Northern Italy). She told me that her uncle, an 88-year-old man who had had a stroke almost a year ago, was getting worse by the day due to the limitations on social life and the interruption of rehabilitation therapy:

Maria: Maybe you should write this in your notes because the isolation is worse for these people who can't understand the laws and have to adapt to all these sudden changes. His partner says that it is not clear if they are allowed to go out for a walk. She used to walk near their house for 30 minutes, taking the hospital discharge certificate with her, because she can't go to her doctor, who is far from where they live, to obtain a certificate for going for a walk. She hopes she is doing the right thing and says that she doesn't care if she gets fined.

This paper will focus on the experiences of home care for elderly people collected during the

first phase of the pandemic in Emilia-Romagna, Italy. The Italian response to the virus has been fragmented so far, due to differences in the way the healthcare system is managed, according to regions and the regulations of individual local healthcare units (CEPIKU *et al.* 2021; PECORARO, LUZI & CLEMENTE 2021). Emilia-Romagna is widely considered in both academic literature and popular discourse to be one of the wealthiest areas in terms of its socio-economic development and welfare system. It is associated with a long-standing tradition of a community-care approach targeted to the prevention of chronic health diseases, where public healthcare services and not-for-profit associations are well integrated (PAVOLINI 2015). Along with the northern regions of Italy, it has had one of the highest infection rates, yet some public health studies state that the community care approach turned out to be one of the most effective compared to other regions. A study that compared the number of infections, hospitalisations and deaths between Lombardy, Veneto

and Emilia-Romagna in the first pandemic phase, between February 24th and April 29th 2020, affirms that a community care approach – which belongs to Emilia-Romagna and Veneto – was able to cope better with the phenomenon than a hospital-centred care approach – which belongs to Lombardy (PECORARO, LUZI & CLEMENTE 2021).

However, this article will not deal with the problem of evaluating Emilia-Romagna's response to the pandemic; it will, rather, use daily-life fragments to show how a small, interconnected group dealt with family care for elderly people in Italy during the first phase of the pandemic. Managing chronic conditions at home during the spread of an infectious disease presented many threats to different actors. "Home" and "family" care meant having to "tinker" (MOL, MOSER & POLS 2010) with risk rather than just avoiding it, for not taking any risks was not possible. This text offers a broad understanding of the "family care" system, which includes also the care provided by home-care workers. By showing how the pandemic met with pre-existent fieldwork relationships, I will discuss the relationship between chronic diseases, forced isolation, and care activities. The text takes into account how community acts of care and reciprocity played an important role in filling the gap left by institutions and public care services. I will observe how the pandemic not only altered a previously established balance in moral and social life but also worsened pre-existing structural inequalities in the local elderly care systems. In this sense, the view of the pandemic as a "radically new" crisis is both accepted and critically questioned in this essay.

Elderly care has often been described in scientific journals and in the media as one of the sectors hit hardest by the pandemic for the many elderly people infected and dead in nursing homes, or forced to live in isolation at home even for months (HEID *et al.* 2021; MANDERSON & LEVINE 2020). However, this perception of the pandemic as primarily of concern for "elderly" and "vulnerable subjects" has been the source of a revival in ageist feelings around the world, exacerbating both discriminatory and paternalistic attitudes to the "fourth" age group (ALLEN & AYALON 2021; VERBRUGGEN, HOWELL & SIMMONS 2020; SCHROYER 2021; REYNOLDS 2020; PREVITALI *et al.* 2021).

Research reports that when news of high infection rates in residential homes broke in the media with sensationalist headlines, many children and grandchildren felt guilty and/or were blamed for having put their elderly relatives into nursing homes, even when this was the only option to take, while fear and anxiety may have increased among the residents themselves (ALLEN & AYALON 2021). Yet what has traditionally been promoted by institutions and private care agencies as "family care" or "home care" was far from being the heaven it was supposed to be even before the pandemic, due the unintended consequences of the global four-decades-long politics of moving care from hospital to home (KENT, ORNSTEIN & DIONNE-ODOM 2020). My fieldwork highlighted that Covid-19 and social isolation have worsened the condition of people with chronic diseases and their caregivers, who had to manage their everyday needs despite the risk of infection and further limiting of already scarce public services of homecare and semi-residential care. The institutional politics of preventive social isolation, targeted mainly at the elderly, just heighten the limited mobility and social isolation that, without any written rule or explicit statement was already imposed on elderly people with the most severe chronic health conditions and their live-in caregivers (MANDERSON & LEVINE 2020). Numerous research articles on the "caregiving burden" state that unpaid family caregivers' stress has been exacerbated, along with the health conditions of the people cared for (COHEN *et al.* 2021; GULIA *et al.* 2020). However, in this paper I also consider how infection risk and restricted mobility affected the experiences of the home-care workers who, without full public and institutional recognition, provide a fundamental support to the home-care systems in many nations, including This article is part of the ongoing project, "Corona Diaries", launched at the end of March 2020. The project's aim was to collect ethnographic diaries about the pandemic that include "descriptions of situations, descriptions of one's own behavior and the behavior of others, notes of conversations, reflections, fragments of thoughts" from researchers' own environments.² With this aim, I started collecting phone interviews, WhatsApp messages, email exchanges, newspapers and journal articles every three to four days, or weekly, in a city 40 km away from my research location in

Emilia-Romagna. In Emilia-Romagna, I had previously been undertaking ethnographic research for my Ph.D. project on community-care services for home-based care for elderly people. In this paper, I present a detailed description of different ethnographic vignettes around multiple fieldwork topics. I found in my fieldwork that my respondents acknowledged how the lockdown was provoking potentially serious short- and long-term consequences for people: those affected by neurological diseases, who were experiencing great difficulty in getting physical exercise either inside or outside the house due to the interruption of rehabilitation therapies; family members who needed to rearrange care activities due to the closure of adult day-care centres and the interruption of private home-care work; and also home-care workers who lived in conditions of forced isolation or did not know if they would have work and receive wages in the following weeks or even months.

An almost apt prediction

At the end of March 2020, I received an email from Graziano, a middle-aged man who is one of the few male home-care workers in Italy. In the previous days I had been sending messages and emails to all my home-care worker acquaintances informing them that I was collecting lived experiences about the pandemic for a collective research project. I had previously interviewed Graziano for my doctoral research project on elderly care in Emilia-Romagna, and we spent almost an hour talking about care work sitting on a park bench. I met him in 2019 on one of the refresher courses on home care organised by the local social services with the support of many healthcare professionals. The person responsible for the home-care training project, Carla, presented him to me as one of the workers I “must interview. And that is because he is one of the most experienced and finest of them.” He had already successfully completed the course and received the certificate of trained home-care worker in 2012. He had been previously working as an accountant for a small company until it went bankrupt in 2010 due to the financial crisis. He discovered this municipal home-care course thanks to his sister while he was attending many other courses through the employment office. During the interview, he told me that he was living in the

house his mother gave him when she moved into a smaller flat. He has no children, no home loan to pay. He has one sister, but he has always had a special relationship with his mother, who has often confided in him and asked him for help to buy medicine or to take her to medical examinations. His mother, whom he proudly described as a perfectly lucid woman despite her age, has had a knee replacement and some back problems so she needs to help with housework as well as being accompanied when leaving the house. Thus, 5 years ago, his mother offered to officially employ him as her care worker rather than looking for another one, and he accepted. This is not a common thing, but some research reports that some children, in conjunction with their parents, decide to be employed by the latter as their care workers in order to benefit from regional and municipal cash-for-care vouchers (MINELLI & REDINI 2015)³. He had also been taking care of a family friend, Giacomo. Graziano and Giacomo’s son were best friends, so Giacomo had known him since he was a child, but his son died some years ago. During the funeral, Graziano promised Giacomo that he would be there for him for whatever he needed. Since then, the two became friends and Graziano has generally helped him by talking with his family doctor, writing mails, and making him to appointments for hospital visits. Unpaid. In the email, he wrote that he had suspended all his jobs apart for caring for his mother and Giacomo. He also made an almost catastrophic prediction about the pandemic:⁴

Graziano: Hi Francesco. I’m glad you wrote to me. I pray I’m wrong, but I feel that this virus will kill millions of people, particularly the elderly and immunosuppressed, prowling around the five continents until a vaccine is found and distributed, that is, in about a year and a half or maybe more. Let’s hope that my predictions are excessively catastrophic and that all this passes quickly. For the category of home-care workers, dark times are in the offing. Many will lose their jobs, and some will lose their residency permits [...] The death of many elderly people will inevitably lead to this outcome, as well as greater availability of time for family members. But I believe that for each of us the most distressing idea concerns the possibility of losing someone who is dear to us [...] our elderly family members are the first we are interested in. We all cherish the hope that

the future, once the storm has passed, will be able to smile at us more than the past did [...] See you soon.

It would be difficult to say whether Graziano's "catastrophic" predictions would prove right or wrong. This was also true of his "utopian" hope about feelings of compassion and solidarity among people. Nevertheless, it is necessary to acknowledge that while everybody in the media and in the popular discourses was stating that the pandemic would be gone in six months or less, he was right to believe that this would not be the case and that many elderly people and home-care workers would experience numerous strains in the following months. The recent data show that in April 2021, one year after Graziano's mail, Italy was still far from meeting the European Union vaccination target, especially for the population aged 80 years or older, although Emilia-Romagna is one of the regions with the best performance nationally (PANORAMA DELLA SANITÀ 2021). While I will discuss the lived experiences of home-care workers later in this article, in the next paragraph I will focus directly on how forced isolation and the interruption of public and private home-care services posed several threats to family caregivers.

The Café community and the "old old"

Mariagrazia: Do you know that the adult daily living centre is closed now? Alessandro told me that he can't rely on them anymore, and he is stuck with his wife at home, and it is the same for all the others. And the problem is that he can't cook, and all the restaurants are closed now, so it is a good opportunity to learn! (laughing) I miss him and Raimondo so much, our jokes and banter at the Café.

I received this call from Mariagrazia on the 20th March. I met Mariagrazia and her mother at the Alzheimer's Café I had attended for a year until it closed at the end of February, two weeks before the first national lockdown on the 9th March. It often happened that members exchanged news about each other, for example when one of them missed one or two meetings, perhaps because his or her health problems had worsened. Phone calls were made, messages were sent and then the other participants were updated in the next meeting.

There was a stable group of 8–9 family caregivers who used to attend every meeting, bringing their spouses (or, less frequently, parents) affected by Alzheimer's disease or dementia. All of them lived near the health facility where the Alzheimer's Café took place. Lisa, the psychologist of the Café, used to call the family caregivers "accompanists", meaning that they accompanied their loved one affected by dementia to do some memory exercises while they, in another room, would take the opportunity to share the daily-life problems they used to encounter. The service was free, and the "accompanists" valued it highly, saying that it helped them to find the energy and positivity to carry on despite the illness. Many of them also used to meet outside the Café, for example going out for dinner. Many families with an elderly member affected by neurological disease reminded me that they had lived almost in isolation even before the emergence of covid-19. Once one of the Café participants told me that it was easier when they went out for dinner with each other, because often other people did not like the company of their wives or husbands with Alzheimer's, even if they did not say so explicitly:

Maybe they ask you, 'Is she coming too?' Of course, she is, she is my wife. How do they think I would feel if I went out for dinner and left her at home alone? Anyway, I understand them, and I can't force anyone. You find yourself with fewer friends in the end. So it's easier if we go out among ourselves [the members of the Café]; we understand each other better and everything seems normal: no one feels uncomfortable.

The regular group included Mariagrazia and the two people she was talking about during the phone call, Raimondo and Alessandro. Mariagrazia brought her 80-year-old mother, Donata, to the local Alzheimer's Café in 2019, after her geriatrician had told her that her mother "was cognitively ok" but needed to be in the company of and socialise with other people of her own age to alleviate the depression and loneliness that comes in old age.

Thanks to Mariagrazia's several phone calls, I came to know that Alessandro's wife had a serious early-onset dementia condition that left her almost unable to speak. In the end, also thanks to Café meetings, he decided to send a request to the

adult day-care centre which took care of his wife during the daytime. But after the virus spread, the adult day-care centre closed and the care worker he employed left. He found himself with no help. After the first call, Mariagrazia told me that during the lockdown she used to “send” his husband with some delicacies, such as a home-made lasagna emiliana, to Alessandro’s house, with a believable excuse for police officers, “and he appreciated it” (laughing).

Maria later explained more about Alessandro’s situation. Maria was a home-care worker who attended the Café because she brought there one of the old ladies she was assisting. For her it was work, yet the psychologist was a strenuous promoter of letting home-care workers attend the meetings, and when they offered breaks dedicated to the caregivers – such as relaxation exercises to relieve stress and tension – she was concerned that they too should receive them. Maria too was concerned about Alessandro:

Maria: I spoke to Mariagrazia, who is a very good person, and we are worried about him. Because I know that he isn’t doing well, because Maria (his wife) is seriously ill, and I know he can’t do housework. He had a girl who came in the morning, woke and dressed his wife, did the cleaning and then cooked something for lunch. I know they often went out to dinner because they are wealthy, but now everything is closed. Mariagrazia told me that she brought him food a week ago, so I thought that since he lives near me I could bring him some stuff sometimes and give him some advice. I hope he will be pleased because I am not very confident with him, and I don’t want this to turn into a full obligation because I must also take care of my uncle.

Like Maria, I have always respected Alessandro’s silence about his situation and story: before the lockdown I had suggested an interview several times, but he always avoided the question. I decided to include his story in both my diaries and the article because in the end he himself told it to me. This happened when I decided to share a blogpost on the Alzheimer Café’s *WhatsApp* group, which was a substitute for physical meetings. The post was published in Italian on my university’s ethnographic blog on the pandemic and isolation, “The Right Distance” (*Osservatorio la Giusta Distanza*), on 20th March. I wrote about the effects of the pan-

demic on elderly care that I had noticed from my field research. When I was writing it, I realised it would be a collection of disasters and apocalyptic previsions. Thanks to my past experiences at the meetings, I thought that many of the caregivers in that group could also share an approach more oriented towards finding positive aspects and optimistic beliefs. So, I included this concluding statement:

To conclude, it seems that the impacts of the period of isolation and the spread of the Covid-19 virus on care work are extremely significant [...] In this text, however, there are no references to ritual behaviours to ward off fear – among which, as always happens in these cases, irony plays an important role – and above all references to adaptation strategies implemented that are certainly present (DIODATI 2020).

When I shared this post on the *WhatsApp* group, I received many kind responses (as usual) but one several critics from Alessandro himself. He texted on the group that he couldn’t rely on the local adult day-care centre and the woman who had been hired to help him assisting his wife with a serious dementia condition any more: “And I can guarantee you that it is a much bigger problem for anyone who is in the worst state of health, and there is no adaptation strategy as you wrote!”

Two weeks later, Maria phoned me to explain the situation she was living through with her uncle:

Maria: Apart from the coronavirus, assistance must be guaranteed for some pathologies. My uncle is accustomed to staying with me as well as his partner, and he has a cognitive decline, so he doesn’t understand the situation. Now it seems that with the new self-certification you can also move between the municipalities to assist an elderly relative, so last week I saw him more often. I see he is getting worse. This morning I managed to get a walker from a lady because I have many contacts with people I have worked with and helped, so now I can ask for help. A walker seems nonsense, but it helps those who have mobility difficulties to walk more. And it’s good for him to walk and see other people.

When she started caring for her uncle during the pandemic, she used the group chat to let off steam. She said that her uncle was always used to

being with her, and they had lunch together every now and then. Her uncle had grown accustomed to her presence and was struggling to accept their separation during the lockdown. A few months later, in June, she explicitly complained about his girlfriend returning to her family, saying that she had turned out to be an “unreliable person who had run away”.

The isolation brought several problems for elderly people and their caregivers as well as exacerbating some ageist feelings toward the former. A quantitative survey carried out in the USA reports that elderly people suffer greatly from the loss of social activities imposed by lockdown, such as visiting friends and family, going to the gym, volunteering, or going out for a walk (HEID *et al.* 2021). It is useful to recall that these activities have long been what healthcare practitioners and institutional discourse have themselves prescribed for elderly people, in order to preserve their independence and autonomy as long as possible. Remaining active and socially connected is widely considered the way to age well almost everywhere in the contemporary world. For example, here it is the testimony of Sandro, whose wife has a serious Parkinson's condition:

Sandro: We often go walking because Gianfranca is always ‘stuck’ when she gets up in the morning and then she gets unstuck little by little. We had to stop doing it because there were too many people and it became too dangerous, and now we go only around our house. We need to avoid contagion because if Gianfranca is hospitalised she will have problems following her therapy – she takes about twenty or thirty pills a day – and I will not be able to visit her. I’ve seen incredible things: five people taking the dog out, teenagers sitting with their smartphones and chatting. We have got a good reason to go out but there is too much irresponsibility around. I think that the most irresponsible persons are teenagers and the ‘old-old’ (I’m old, but I’m only seventy-four years old). For example, a friend of mine is ninety-two years old and habitually buys groceries twice a day: he said he has always done it this way. What does it mean, ‘I’ve always done it this way’? He is crazy!

During the first months of lockdown, I wrote in my diaries how some neurologists and activists were claiming in media that forced isolation was affecting people who need to do physical activity

because of serious ailments, such as the aged population. Some of these claims certainly showed a paternalistic attitude to the “fourth” age group. For example, a local online newspaper published an interview with a psychologist who said:

Many people [caregivers] tell me that elderly people have a low perception of risk, so they struggle to communicate to them the correct behaviour to be followed. Why? They have often less access to data or less understanding due to low schooling [...] It is important to try to explain this situation to the elderly, trying to maintain an empathic attitude and using simple language and repeating if it has not been understood (BERTOSSO 2020).

Ethnographic research in Denmark and the USA shows how many people in their sixties, seventies, or even eighties simply refuse to be permanently categorised as “at risk” or “vulnerable”, as though becoming old or even just entering the “third age” automatically means developing severe diseases or losing cognitive function (CLOTWORTHY & WESTERDROPP 2020; LAMB 2020). Apart from this, others have written about the serious long-term consequences of forced isolation on the management of chronic diseases. Among those, a famous Italian neurologist and leading expert on Parkinson's disease advocated for a special national unit for the management of chronic diseases which would be able to take uniform decisions for the whole country (IL MESSAGGERO 2020). The doctor was well known among my interlocutors who suffered from Parkinson's disease, and in the article, he reported what he had repeated to them many times, which was that physical activity is essential to fight the illness. He believed that people should not forget that there are many exercises that can be done at home. Indeed, my interlocutors, such as Sandro's wife, did plenty of therapeutic and rehabilitation exercises at local community-based health programs before the lockdown. They also joined in with enthusiasm with many of the free activities, such as tango therapy and walking groups, organised by the local primary care unit to carry on prevention activities for disorders related to age. Indeed, these activities have been promoted as the way to age successfully, achieving physical and mental benefit while stimulating sociality in old age (KOH & NOH 2020; PINES & GILES 2020). One of the most enthusiastic par-

ticipants was Gregorio, the founder of a local Parkinson's association. When I phoned him during the lockdown, he stated that he fights against depression and anxiety by keeping his mind trained (he follows online courses on the Japanese language, reads a lot of books, and more), but he also recognised that he could be "lucid and objective" because he was a pensioner and did not have to worry about economic problems in this crisis. We discussed whether someone could really do special physical exercises for Parkinson's at home without a professional expert:

Gregorio: You can do something but it also depends on the severity of the disease and on your ability to use technology for following online demonstrations. Doing the wrong exercises can cause harm, as well as not considering bodily limits, or acting as if you were a superhero.

Associations have tried to support their patients by answering their requests and questions by phone or online, "but solidarity and support have been done on a non-institutional level, as always on an..." [voice trailed away]. "An informal level: if you have a friend, or relative, or if you know someone you can ask him for a favour", I said. "Yes".

The normative cultural model of active aging usually excludes those with many health problems who are unable to age "successfully", exacerbating social blaming toward them (LAMB 2017). The possibility to age successfully depends on the care resources that are available in a specific context. MUEHLEBACH (2012) highlights how the rhetoric on active aging and anti-ageism have, since the 1990s, supported very controversial reforms in the peninsula, based on privatisation and cutting public funding for care services. The neoliberal ethic of active citizenship and voluntary work, built on the Christian virtues of solidarity and "free" care work (*gratuità*), has progressively replaced a vision of the welfare state in which the State should be the guarantor of the right to assistance, rather than communities and individuals themselves. In the absence of public health care services, informal care network filled the gap left by state-based care during as well as before the pandemic. This is especially true of the Italian case, which has traditionally relied upon family networks to provide

care for elderly people, sustained through migrant home-care work (DEGIULI 2010).

Home-care workers and social isolation

Maria: I do not work but I'm thinking about those two ladies: their daughter is stuck in Paraguay. I have to get supplies for them because the home-care worker cannot leave them alone even for an hour. And when she really needs to go out, she must lock them in because there is a risk that they will go out alone. So once a week I go shopping at the big supermarket that costs less, and the home care worker just goes to buy a few things at the shops near the house [...] Do you know that I have been enrolled in the Employment Centre since 2013 and they have never called me? Two days ago, they asked me to go to work in an RSA [the Italian residential structure for people who are completely not self-sufficient]. Domestic care workers can't work in an RSA. I replied: 'Are you crazy? You never called me and now you ask me to go to an RSA without training. I have always worked in home and it's different, I'm not cannon fodder!' (Phone Interview).

While the research field on the caregiving burden has acknowledged how during the pandemic the family caregivers' stress was exacerbated in many countries (COHEN *et al.* 2021), it is important to mention that paid home-care workers have also been affected by pandemic. In Italy, home-care workers have sustained traditional cultural view of caring for elderly people at home (DEGIULI 2010). In this section, I consider how home-care workers have experienced the pandemic.

I first met Maria at one of the home-care training sessions organised by the local social services such as Graziano, and then after some months we reconnected at the Alzheimer's Café. She is an experienced home-care worker, who joined the training courses because she was in search of some specific training for a job that she had been doing for several years in an informal way. This project is one of the institutional attempts to shrink the widespread unregulated care market and at the same time support Italian families in employing home-care workers (PASQUINELLI & POZZOLI 2021). It provides training courses for home-care workers (including lessons from nurses, psychologists, psychiatrists, and employment

agencies on age-related diseases, hygiene practices, use of daily living aids, and employers' rights and duties); the trained workers are not directly employed by municipalities but they are recommended to the families as qualified and expert professionals by the social services, which manage and mediate the employment relationship between workers and families, also organising counselling services and self-help groups for both home-care workers and family caregivers. Maria always stated with pride that she did not need to be promoted to families by local social services because she had several contacts and requests.

Coming back to Graziano's prediction in the middle of March, in the following months many other home-care workers involved in the local home-care project bore witness to me about the fear and uncertainty they experienced, as in the following two diary fragments:

28/03/2020

Anna told me that social services (who employ her as a private professional) send all the home-care workers a form to apply for a sort of reimbursement. In the next few days, I will call one of the social workers responsible for the project. Anna's employer, who is a post office employee, has benefited from sick leave to assist her disabled son, but has decided to pay Anna the whole salary for March and even April anyway. Anna assured me that she trusted her employer because she is a respectable person, but I would like to hear of a national law that will not leave home-care work again on the shoulders of 'kind-hearted' people. There is still no financial aid for them, and many associations and media are condemning that.

09/04/2020

I spoke with Lucrezia, who is another care worker employed in the social services' programme for home-care services to elderly people. Her work was suspended in March. She was paid for the first week, in the second week she benefited from paid leave, in the third she lost income. She said she is not going to search for another job because she is afraid for her mother, who needs to be cared for. After the call, I decided to check how private home-care work has been discussed in the media. National newspapers have dealt little with this subject. *Il Messaggero* reported an interview with the leaders of some domestic workers' associations: the president of FIDALDO (*Federazione*

Italiana delle Associazioni di Datori di Lavoro Domestico – Italian Federation of Domestic Care Work Employees) claimed with satisfaction that many families are regularising their once irregular employment, while the president of ACLI-colf, which represents the workers, complained that around 60 percent of domestic care workers lost their jobs. The undersecretary of the Economic Minister promised that a new decree in April will resolve the situation of many workers left without any help from the government. At the beginning of the crisis, the most important Italian economic newspaper, *Il Sole 24 Ore*, reported that the leader of ACLI-colf stated that the national lockdown did not stop domestic care work, and hoped to guarantee assistance only for non-self-sufficient elderly people (https://www.ilsole24ore.com/art/non-si-ferma-lavoro-domestico-ADpFvGF?refresh_ce=1 [10/04/2020]). More recently, the newspaper criticised the government measures taken to face the crisis, judging them insufficient to solve the situation of rents, mortgage rates, and also of domestic care work: only a small percentage of families (13%) decided to pay the entire salary for the suspension period; more frequently they chose to give them paid leave (35%) or unpaid leave (9%). (<https://www.ilsole24ore.com/art/dal-cura-italia-primi-aiuti-famiglie-misure-ancora-deboli-giovani-e-anziani-ADpsHvH?fromSearch> [10/04/2020])

The most pessimistic prevision was confirmed by later data. Very recent research published in April 2021 (PASQUINELLI & POZZOLI 2021: 6) reports that:

The lockdown brought the regularisation of a proportion (however modest) of employment relationships, probably to obviate the constraints on movement in the absence of justified "work reasons". At the same time, especially in the second half of last year, there were several cases of termination of relations. At the European level, there has been a decline in new hires [...] From an analysis carried out in the spring, the ending of contracts, especially in non-serious situations, was a choice that can be found in one case out of four. Many families, being able to stay at home and trying to minimise the risk of contagion, have reduced the work entrusted to domestic workers.

While live-out workers – such as Maria, Lucrezia and Anna – frequently interrupted their jobs or were forced to interrupt them by Italian fam-

ilies, live-in workers often continued their jobs, especially with elderly people who did not have a family network to rely on, and were in critical conditions of social isolation. Live-in migrant care workers have consistently been the largest part of the home-care market in Italy since the 1990s. Several ethnographic and qualitative studies have documented their precarious living conditions within the households, such as the emotional strain and social isolation caused by an almost 24-hour job in which workers are often not allowed to eat food, have a private room or conduct a social life (VIANELLO 2019; DEGIULI 2010). The home-care project mentioned here was designed precisely to highlight this phenomenon, which recently attracted widespread public attention both in Italy and Eastern Europe under the controversial label of *Italian syndrome*. This definition was coined by media and psychiatrists to describe the psychiatric illnesses that affected many care workers who migrated to Italy and found themselves in disastrous working and living conditions, doing a job that they often knew nothing about while struggling to maintain their family and caring networks (COZZI 2019).

The Italian sociologist of care work, MAURIZIO AMBROSINI (2020: 12), wrote on the effects of the pandemic and social isolation as follows:

When home-care workers took care of frail elderly people, in a live-in regime, they found themselves threatened by the same problem: family members who remained at home, uncertain about present and future income, could decide to save on expenses by taking on the provision of assistance directly to relatives. If, on the other hand, they managed to keep their jobs, they first found themselves exposed to a virus that is very threatening for the elderly. Their training to deal with contagion and the provision of protective equipment are in the hands of the employing families, which in turn do not have the technical training to ensure health protection. One wonders if anyone has raised the issue [...] We don't even know how many care workers contracted the virus [...]. Even when they do not run immediate risks, the blocking of social outings and interactions has deprived them of that minimum of breathing space and of contact with the outside world that offers an outlet to those who live with very old and declining people.

During the lockdown, I also decided to ask the manager of the home-care project, Carla, how they were experiencing the situation. During March and April, she had been overwhelmed by users' demands and also decided to conduct a survey in order to let home-care workers receive state reimbursement for the interruption of their job (which eventually arrived to some extent in the following months with the new law regularising migrant workers). The situation was critical because many live-out care workers were losing their jobs, while the live-in ones were isolated because they could not go outside:

Carla: In many cases families have suspended their jobs or care workers don't go any more because they are afraid of contagion. I've done a survey to get an overview of the phenomenon and to obtain reimbursement for them, I hope. Of the 120 people who work with me, 48 responded. I've been asking everyone if they use masks and gloves, but in many cases the elderly families don't provide them or they couldn't find them. Many workers are afraid of travelling because of police controls [...] ... There is this case: a worker stopped by the police. She is very precise, so she took her self-certification with her and also the employment contract, but the police officers complained because they said she also needed a special authorisation from the municipality for travelling from one city to another one. I discussed it with the travel unions and it is not true, so we have got these abuses as well [smiling wryly].

While the paid home-care workers sustain ideas of home care and active aging, which prescribes that elderly people should keep themselves socially involved and avoid as long as possible nursing homes, the lack of formal recognition of their job affected the possibility of providing them a support in the pandemic. The pandemic just worsened pre-existing social and structural inequalities in family care for elderly people. This process resulted in exacerbating the social isolation and material constraints of both care-givers and the cared-for, impacting severely on the quality of care. Regional and municipal home-care programmes, such as the one discussed in this section, which were intended to ameliorate the living conditions of home-care workers, families and elderly people, were affected by the lack of structural reforms of welfare and elderly care. This lack

has been denounced severely times in the last thirty years by Italian experts in welfare and care, who have advocate for the national welfare state to take a better lead in sustaining home-based elderly care through semi-residential care services, public home-care services and structural reforms of the profession of home-care worker (GORI 2012; PASQUINELLI & POZZOLI 2021). The pandemic also posed threats to regions such as Emilia-Romagna, where there has been a traditional system of community-based care services targeted at the prevention of chronic diseases, causing the interruption of semi-residential care services, community-based health programmes and support services to home care.

Conclusion

It seems that the pandemic and lockdown embody what KAUFMAN (1994) described as an inherent contradiction in the modern perception of aging: a battle between conflicting forces of independence and dependence played at the individual as well as the community level. All the people interviewed had to “tinker” with risks (MOL, MOSER & POLS 2010): they needed to balance the “risk” of contagion with the various threats posed to their life by forced isolation and the interruption of care activities both within and outside households and families. Public opinion too easily accepted that the interruption of care activities should be accepted to save individual, vulnerable lives, and for the common good. Elderly care has often been depicted, so far, as one of those necessary sacrifices. The normative model of old age that shaped the pandemic response has just reproduced the long-standing inherent contradictions of active aging, such as the battle between claims to individual independence and calls for the community protection of vulnerable people, and the exclusion that is endured by the group with the most serious health conditions (LAMB 2017). This also includes home-care workers, who have always sustained the home-care system in Italy, as well as values of the “warm family care” environment that shaped that system, including all its inherent contradictions (CAPPELLATO & MERCURI 2021).

It is difficult to make an optimistic prevision of the future of elderly care in Italy, or anywhere else. No demographic projections have confirmed

that the pandemic will interrupt population aging, while some research has stated that the former will have little impact on the latter (WILSON, TEMPLES & CHARLES-EDWARDS 2021). Elderly care remains an urgent issue that populations and states have to face in the present and in the future. We run the risk that the pandemic will increase care needs in the near future, due to how it has impacted the health conditions of people with chronic diseases. As I stated several times in this paper, it seems that pandemic just worsened the already existing social inequalities in care, which cannot be masked by the rhetoric on active aging and family care. These ideas need a serious engagement with structural reforms and cannot be completely left to individual capacities or informal acts of communitarian values and reciprocity. However, the pandemic also makes these issues more visible in the public debate, and many people are asking for changes in the welfare and care system. The final hope is that the debate will finally be able to realise the transformations that we desperately need for the next generations, and that, as an ethnographer of care and welfare, I look forward to observing and reporting.

Endnotes

- 1 I use fictional names.
- 2 <https://boasblogs.org/curarecoronadiaries/> [13/04/2021].
- 3 Cash-for-care benefits are widely used in the Italian care system to promote care in the family and home environment instead of nursing homes (GORI 2012; DA ROIT & LE BIHAN 2019). These benefits are direct payments that can be used to cover some of the expenses of employing a home-care worker. In some Italian regions, such as Emilia-Romagna, these measures have been taken by institutions to shrink the unregulated care market which is very widespread in the nation (GORI 2012; PAVOLINI 2015).
- 4 All the emails, phone conversations and direct quotations from texts have been translated into English from Italian by the author.
- 5 He is talking about “freezing”: “Freezing episodes are sudden, short, transient blocks of movement that occur primarily with initiating walking, turning, navigating through narrow spaces or approaching obstacles” (<https://www.apdaparkinson.org/what-is-parkinsons/symptoms/freezing/> [15/04/2021]).

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