



Recognizing Caregiving Fatigue in the Pandemic: Notes on Aging, Burden and Social Isolation in Emilia-Romagna, Italy

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Abstract

In Italy, the COVID-19 pandemic and its associated lockdowns have provoked potentially serious short and long-term consequences for older people with serious health conditions as well as their family caregivers. With the closure of adult day-care centres and the suspension of private home-care services, families have needed to rearrange care activities and many are concerned about the situation of their relatives in residential homes. This article examines interpretations of aging and caregiving fatigue during the first period of national lockdown in Emilia-Romagna, Italy. The relation between old age, lockdown, and social isolation, with respect to global ideas and rhetoric, focuses on vulnerability, individual autonomy, and caregiving fatigue. I examine how the representation of the 'burden' of caregiving in late age shaped the media depictions, and I analyze it in relation to the meanings of fatigue attached to narrations from family caregivers and the members of a local Alzheimer's Café. I also focus on the life story of one family caregiver to critique the idealized vision of family care that was reproduced during the pandemic. I argue that the recognition of aging and caregiving fatigue during the lockdown reflected pre-existing normative models and structural inequalities of family care rather than radically altering them.

Keywords: aging; caregiving; fatigue; pandemic; social isolation; Italy

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Introduction

At the end of February 2020, the Alzheimer's Café in a small provincial town in the Italian region of Emilia-Romagna closed along with the local senior day-care centre that hosted it. On 20 March, over a week after the national lockdown, I phoned Mariagrazia¹ to follow up on my intention to investigate how the pandemic was radically altering the everyday lives of the people I had met during my fieldwork. I first met Mariagrazia and her 80-year-old mother, Donata, at the Alzheimer's Café, which I had been frequenting since 2019. Donata had been living next door in the same condominium as Mariagrazia and her husband since Mariagrazia asked her to move there in 2011, when it seemed to her that her mother was no longer able to live alone in her house in another city. Mariagrazia brought Donata to the local Alzheimer's Café after Donata's geriatrician had told her that her mother "was cognitively ok" but needed to be in the company of and socialize with other people to alleviate the depression and loneliness that comes in old age. With her sense of irony and humour, Mariagrazia confessed to me immediately that nothing had changed in her relationship with her mum: she still had a hard time relating to her. "It seems to me we have nothing in common, so we still can't stand each other." She continued:

You know, my mother is in better shape than the other people [at the Alzheimer's Café]; she has just a little bit of depression and her legs are not as good as they were in the past, but she doesn't have dementia and can still take care of herself alone... Despite this, she always complains about everything: for every little ache and pain, the medicines—she takes almost *a quarter* of the pills that the others have to take—people in the streets—"she gave me a bad look." She believes I'm a bad person who treats her badly and doesn't understand her, even if she doesn't say that directly—she is sneaky. Yesterday, a man was singing on the balcony—you know, all this kind of things like singing and playing music on the balconies that makes you happier—but she said he sucked, everything sucks, always. And then we had an argument about that. [phone conversation; 8 April 2020]²

Mariagrazia is a 50-year-young grandmother; she was missing her grandson and was worried for her daughter and her husband because he worked as a sound technician for public events, which were all suspended until an unknown date.

Almost a week after that conversation, I phoned Tommaso, a middle-aged man who had been attending a self-help group for family caregivers because he had cared for both his parents, who were affected by dementia. He continued to attend the group even though his father had died in May 2019 and, in the same month, his mother was admitted to a residential-care facility in the same city where the Alzheimer's Café was held. The day the local nursing home started to forbid family visits, he had just

arrived there because, as he said, “I could smell that the situation would change soon,” but the staff did not let him in. At that time, he was living with his mother-in-law and his ex-wife.

FD: You are a lucky man.

Tommaso: Oh yes (*laughing*). They were renovating the house but now it is all interrupted due to coronavirus, so they came here with me and I’m living the same odyssey again. My mother-in-law is one of those who’s always saying, “I would like to die” – and my ex-wife has no patience with her, so it is up to me, and in the evening I’m exhausted. The [caregiver support] group has been interrupted, and no, I don’t know anything about the others. I’ve tried to phone my mom because yesterday was her birthday, and I’m a bit sad we didn’t celebrate together as usual, even if last year she didn’t recognize me. I don’t hear anything about how she is now; they (at the nursing home) only call you if something bad happens. I hope the virus doesn’t spread here as I heard happened in Piacenza [40 km away] because it would be like an atomic bomb! [phone conversation; 15 April 2020]

Based on ongoing ethnographic fieldwork in Emilia-Romagna, Italy, this article aims to inquire about the social recognition of the deleterious changes in old age. In particular, I examine the way this notion articulates family life and responsibility for care in the household (Cohen 1995, 316-319), which shaped the first phase of the pandemic response in Italy. In this article, the COVID-19 pandemic and its associated lockdown are considered with respect to global ideas and rhetoric about aging, vulnerability, individual autonomy, and caregiving (Lamb 2017, xi-xv). In this article, I move on from these previous works and analyses to examine the representations of aging and caregiving fatigue that have emerged during the initial period of national lockdown from March to April 2020. Rather than insisting on the idea that a pandemic radically alters social relationships and global social structures,³ I focus on how social norms and structural inequalities were reproduced via the isolation politics in Italy.

First, I examine public constructions of the ‘burden’ of old age during the pandemic that have emerged in social networks and newspaper articles, particularly the media’s and healthcare professionals’ depictions of older people as vulnerable and posing a risk to themselves and others. This also concerns discourses and experiences about residential-care facilities, where viral contagion reached a critical point. Lastly, I explore the life story of one family caregiver: this life story is presented in order to grasp ideas about and normative models of sociality, family life, and responsibility for care in the household.

Ethnography of Aging and Caregiving During the Pandemic

At the end of February 2020, I was in the most intensive phase of my fieldwork during the second year of my Ph.D. in social and cultural anthropology at the University of Milano-Bicocca. For a year, I moved around support groups, home care training courses, and public conventions on caregiving in the province of Bologna. I was interested in studying the relationship between population aging and the normative model of ‘the family caregiver’ that has recently emerged globally in social services, healthcare services, and activists’ debates (Leibing 2017; Sadler and McKeivitt 2013). Emilia-Romagna is one of the wealthiest regions of Northern Italy and, in the national imaginary, is seen as the rich and happy ‘Sweden of Italy’ due to its progressive welfare and healthcare services (Pavolini 2015, 125). For the last 30 years, Italy has had a mixed model of welfare, fragmented into regions and municipalities, which has relied mainly on private home-care services. These workers are mostly recruited from the migrant population to attend directly to the needs of older people (Ascoli and Pavolini 2010; Bifulco *et al.* 2007; Pavolini and Ranci 2008). Recently, thanks to the advocacy actions of newly created Italian caregivers’ associations, public attention has also focused on the emotional exhaustion and social

isolation that workers experience while providing intensive assistance to people affected by neurological diseases. In the last 10 years, there has been a proliferation of respite care programs for family caregivers in the Northern Regions; this includes adult day-care centres and community services such as peer-to-peer caregiver support groups and Alzheimer's Cafés run by local social services and social agencies (Pavolini and Ranci 2008; Pavolini and Spina 2015).

When the Italian Prime Minister declared a national lockdown on 9 March, I had just left my fieldwork site. All the activities I was attending—Alzheimer's and Parkinson's cafés, caregiver support groups, home care training courses—were just suspended by a regional decree until an unknown date. Since then, like many other colleagues, I have tried to document in writing the changes and transformations that happened during my fieldwork and my own living environment at the same time I was experiencing them. I have also been part of the ongoing project "Corona Diaries" launched at the end of March 2020 by *Curare*, the journal of the Association for Anthropology and Medicine. Here, the aim is to collect ethnographic diaries about the pandemic that include "descriptions of situations, descriptions of one's own behaviour and the behaviour of others, notes of conversations, reflections, fragments of thoughts"⁴ from researchers' own environments. With this aim, I started collecting phone interviews, WhatsApp messages, email exchanges, newspapers, and journal articles weekly for every three to four days in a city 40 km away from my own research area. In many cases, caring for a family member or working as a domestic care worker does not leave very much free time to spend with a stranger/researcher. With some of these caregivers, in-depth telephone interviews about their life stories were the first interviews I was ever able to conduct with them. In some cases, particularly with people who had frequented the suspended Alzheimer's Café, phone interviews became a ritualized practice during pre-arranged moments—for example, when the older person was sleeping in the afternoon or was with the domestic care worker in the morning. These moments offered the chance to share what they were experiencing, just as they used to do every Friday at the Café.

Our conversations often turned to how COVID-19 seemed to affect their daily life. The caregivers acknowledged that the lockdown was provoking potentially serious short and long-term consequences for older people. In my fieldwork, I spoke with: caregivers of elderly people affected by neurological diseases who were experiencing great difficulty in doing physical exercises either inside or outside the house due to the interruption of rehabilitation therapies; family members who needed to rearrange care activities after the closure of adult day-care centres, and who were struggling with the decision of whether or not to suspend private home-care services; and those who were concerned about the situation of their relatives in residential homes, where the viral contagion often appeared to be devastating. That issue appeared side by side with many long-standing popular and media depictions of the irresponsible behaviour of old people who did not care about their health, and who were stealing scarce and precious economic resources from the community.

Similar representations of the "burden" of older people on the community in the COVID-19 pandemic can also be found in medical anthropologist Rebecca Irons' discussions about intergenerational conflict and discourses about "the boomer remover" and the "greedy old" society in Britain,⁵ as well as in the blaming and accusation of the "selfish" Japanese elders who stood outside drugstores to take the first few masks available in the country.⁶ Many studies document how the COVID-19 pandemic has been the source of a revival in ageist feelings around the world (Previtali *et al.* 2020; Reynolds 2020; Verbruggen *et al.* 2020), and they emphasize how family caregivers' stress has been exacerbated along with the health conditions of those receiving care (Kent *et al.* 2020; Cohen *et al.* 2021; Giulia *et al.* 2020; Russel *et al.* 2020).

COVID-19, Senility and Family Care in the Media

Initially, politicians from both the government and opposition parties, national celebrities, and some popular scientists assured everyone via the Italian media and on social networks that it seemed like the virus was dangerous only to frail people, such as the very old and people with a serious chronic illness (Dubois 2020; Marrone 2020). The media campaign “stay home and stay safe” was targeted mainly at older people, encouraging them to limit their social life while urging family members and other citizens to look after these most vulnerable members of the community (Fabretto 2020). This included committing to buying essential goods for them, such as groceries and medicines, so they could stay at home while paying particular attention to wearing masks and keeping a safe distance away from them.

In an article titled “The Difficulties of Sick People and Caregivers During Isolation” [*Le difficoltà di malati e caregiver durante l’isolamento*] (Di Todaro 2020), one of the most popular Italian newspapers *La Stampa* reported on an interview with the director of a neurogenetics center in the south of Italy. This neurologist discussed the dramatic situation of patients affected by dementia who were being forced to stay home:

I am concerned about Alzheimer’s patients for whom not being able to go out for the usual walk can mean an increase in anxiety and therefore a worsening of their health. In addition, the closure of health and social care places, such as medical clinics, Alzheimer’s cafés and day-care centers, means that the care of patients seriously affects their families who, without those few hours of relaxation, cannot recover the physical and emotional energy to support these patients. There is a risk of increasing behavioural disorders, not only in the patient but also in the family member themselves.

The neurologist also stressed the importance of providing support for family caregivers of people with dementia; particularly, in relieving their feelings of fatigue and exhaustion:

A vicious circle must be avoided by helping caregivers [...]. It is a disease that affects the whole family and impacts the lives of all family members. In these quarantine days, patients forced to stay at home can become more agitated, aggressive, and therefore more demanding.

Newspapers discussed the idea that the pandemic would be a disaster for older people, and therefore for a large part of the population in one of the oldest countries in the world; for example, on 5 April the economic newspaper *Il Sole 24ore* published an article on COVID-19 death rates titled “The Italy of Our Boomers’ Grandparents Will be Wiped Out by the Coronavirus” [*Quell’Italia dei nostril nonni e del boom economic sarà spazzata via dal Coronavirus*] (Bricco 2020). A local newspaper in Emilia-Romagna, *Bologna Today*, also reported an interview with a psychologist working in a residential facility; the aim was to expose the “consequences of coronavirus on older people and caregivers” (Bertossi 2020). Talking about how she worked through phone conversations, the psychologist underlined the fact that older people were among the most vulnerable during the period of forced isolation because they also lacked the ability to understand and react to the situation:

Listening to the stories of my patients, I noticed that almost everyone talked about the way they were concerned for the health of their dear older grandparents or parents. In emergency situations, everyone activates their own resources and ways of dealing with stress; however, there are more vulnerable sections of the population, such as people of a certain age. In this pandemic, it was immediately clear that older people were the

most at risk of getting sick, but it is important to remember also, in addition to physical health, the pandemic can have a strong psychological impact on older people, or can exacerbate psychological disorders or pre-existing psychiatric conditions.

At the end of the interview, the psychologist also offered some advice to caregivers, such as trying to maintain a normal routine of day and night, making video calls with relatives and friends, and asking health professionals for help. She explained the recommended attitude to adopt with older people: “It is important to try to explain this situation to them, trying to maintain a compassionate attitude while using simple language and repeat if it has not been understood.” That is because:

A concern often reported to me was the low perception of risk by older people, with consequent difficulty in communicating to them the correct behaviours to follow to limit the risk of infection. Because? They often have less access to sources or less understanding of such a complex phenomenon due, for example, to low education. ...

In contrast with these representations of older people as vulnerable subjects who lack the ability or education to react to and cope with the changes brought on by the pandemic, Lisa, the psychologist at the Alzheimer’s Café I had been attending, published some reflections about her work experience in a residential-care facility. Released in a local online newspaper at the beginning of May 2020, she aimed to give positive thoughts about older people⁷:

The fact of having identified a majority of positive effects compared to the negative refutes one of the most widespread stereotypes about seniors – that of a lesser ability to cope with change. This is a scientific fact. Our ability to cope with events and adapt to new conditions can improve over the years, and it is as if we become increasingly resilient, contrary to what we imagined. [Older people] have a psychological force and creativity that we often do not consider.

Lisa emphasized what she had been repeating during the Café encounters: in her view, old age is not necessarily a time of anxiety and giving up; rather, old age can also be a life stage of resilience and positive transformations.

In contrast to what the other psychologist believed about vulnerable older people being unable to understand and adapt to the new pandemic conditions of living, Lisa said that among her patients:

There is a greater awareness of everyone’s individual role, responsibility for collective well-being; for example, also in compliance with the rules for hygiene and protection that this pandemic has imposed on us. Older people in the building are not obliged to wear masks, but someone asked us to wear them after hearing the news on TV. One of the positive aspects I have found is that this quarantine is being seen as an opportunity to reflect and dedicate oneself to things worth living for.

During April and May 2020, Lisa posted photos and videos on social networks that portrayed smiling older people in wheelchairs at the residential-care facility, holding signboards translated into the local dialect with institutional pandemic slogans about the safety measures everyone should adopt to protect oneself and others: “wash your hands,” “wear masks,” “keep a safe distance” –but also positive messages as “everything is going to be all right.” Immediately after the national lockdown in March, she created a WhatsApp group for the family members at the Alzheimer’s Café, which she utilized as a surrogate for the physical café, inviting participants to share “oddities and curiosities that our dear ones

with Alzheimer's are doing during this quarantine period." As she told us when she shared that interview in the WhatsApp group, she aimed to speak against an excessive dramatization of the events—particularly in the case of residential-care facilities—which seemed to leave no space for positive attitudes and psychological wellbeing.

One evening at the beginning of April, on her way back from work, Lisa wrote a short post on Facebook in which she said she felt inspired by the way her patients were reacting to the pandemic—with little self-pity and a huge sense of irony—something that gave her the strength and capacity to endure in these hard times. In the interview, she also spoke about the use of social media as something effective in maintaining ties and the relationships between patients and relatives. To her, those results refuted stereotypes about older people not being able to use modern digital technologies:

Even this stereotype one must abandon: the idea that older people are generally resistant to and almost reject the technological medium, while I can personally guarantee that, apart from the initial amazement of seeing loved ones on video, they have a great capacity for adaptation. Two ladies equipped with smartphones have even independently enhanced their use of technology through video calls and social networks. In general, we do not tend to attribute this attitude to an older person and yet they can use social media and smartphones . . . Therefore, older people are more connected and happier.

Following the same line of thought, the social agency in charge of the residential-care facility had spread photos on social networks documenting the video-call conversations between residents and their relatives. This social agency is one of those that allowed the residents to make video-calls with their relatives to maintain some form of personal and direct communication during the isolation period when physical family visits were forbidden in care facilities across the country. By posting photos that portrayed people maintaining affectionate relationships and emotions through technology, the social agency's managers were directly and indirectly declaring the agency's commitment to high-quality care standards. I decided to phone Lisa in April, one month before her interview was released on the online local newspaper—the same interview was also reported briefly in one short item of the local news, where many of the Café's participants learned about it—to obtain some information about how residential-care facilities were experiencing and managing the pandemic. I realized that many residential-care facilities—but not all—were trying to organize virtual, 'alternative' possibilities to the physical interactions between residents and their relatives. At that time, news about the contagion in residential homes was beginning to spread more consistently; among my informants, this produced tragic and apocalyptic visions about the future of the oldest members of the community. Lisa had already written a message in our WhatsApp group two weeks earlier, in which she answered questions about how she was dealing with the situation, and confessing to being very worried about working in a residential home:

. . .Where contagion seems to be only a matter of time. My moods flow between feeling calm, focused, and determined to feeling confused, nervous, and afraid. In the last few days, I've also realized I have rigid muscles in my neck and my jaw is clamped shut, clear signs of the tensions and stress I've been experiencing. It's also true that working offers me the chance to have some social contact with my patients and my colleagues; otherwise, I would be alone at home. I will take advantage of next weekend to rest. I hold you all in my heart <3. [message on WhatsApp group; 21 March 2020]

One week before the closure of the Alzheimer's Café at the end of February 2020, Lisa had lashed out on Facebook about her anger when dealing with family members who were unaware of the protective measures to adopt with their relatives in the residential-care facility where she worked. In the end, the managers of the facility succeeded in taking preventive measures, such as using sick leave for the health workers who showed suspected early symptoms; at the time, there was only one suspected, yet not confirmed, coronavirus case. For this reason, the residential home attracted media attention, at least locally.

In the Italian context, population aging and welfare restructuring emerged alongside institutional discourses about the dependency ratio of the "oldest old" in the population (Greenberg and Muehlebach 2007). In the first discourse of the first psychologist, older people were represented as vulnerable and passive subjects during the pandemic, while it was assumed that family members needed to care for them. In this sense, the recognition of "senility" links vulnerability in late age to normative notions of family responsibilities to care for older people through the medical and institutional environment (Cohen 1995, 316-319). However, in the view of Lisa, old age is neither a passive life stage nor an age of dependency: she pointed to the way people in later life can make a positive contribution to society and community, even in the midst of a pandemic. She stressed how older people can develop a different perspective on their life stage and remain open to self-change, which is generally assumed to be related to young people and adults. In both her public interview and in the photos with seniors smiling and holding institutional slogans about the safety measures to adopt, older people are no longer a vulnerable group who, through no fault of their own, constitute a burden for their family and the society at large; rather, these people emerge as responsible citizens who are able to adapt to new transformations, and are thus to care for themselves and others. Furthermore, Lisa underlined how residential homes can develop forms of sociality that are not opposed to the notion of "home" care widely used to talk about forms of care that emerge in the domestic environment (Visser 2019). News about the contagion in care facilities increased the stigma and mistrust of these care settings around the world (Allen and Ayalon 2020). This is especially true for Italy, where institutional discourses have often promoted home care with the help of private home care workers as the option preferable to a residential-care facility because it tends to keep older people in their "warm" family environment (Degiuli 2010). In the next section, I show how in my fieldwork the contagion in residential-care facilities worsened the social blaming of patients' relatives accused to do not care about their older loved ones.

Residential-Care Facilities And The Moral Blaming Of Patients' Relatives

While in the public interview she emphasized that older people can also adapt to new changes, Lisa privately confessed to me, referring to video-calls between institutionalized patients and relatives:

These are ambivalent tools; sometimes, they only increase anxiety and fear, and people with a serious cognitive deficit also can't use video calling appropriately, and they are of interest only to relatives, not to patients. I realized also that my mediation is fundamental because I saw that people, whom I know had not previously accepted it and had felt guilty for having their loved one in a residential facility, are now very worried: "Why does he look so pale? Oh my God, he is sick, is dying!" And I try to bring everyone back to reality. [phone conversation; 12 April 2020]

Social-media platform have fostered communication and affective interaction between older patients and family members who were forced to stay away, confirming the fact that digital technologies can effectively function as a path between older and younger generations (Danelly 2015; Kaplan *et al.* 2015).

At the same time, the last fragment shows how those technologies can have ambivalent effects, creating more family pressures and social expectations that are often difficult to satisfy (Nedelcu and Wiss 2016, 216; Peletz 2000). Furthermore, while Lisa publicly advocated for a more positive view of old age against the social representation of the vulnerable and burdensome older people, she also acknowledged that elders with the most serious health condition could be left out of the global discourse about “active aging” (Lamb 2017; Rickli 2020).

Returning to my conversation with Tommaso—a middle-aged man who had been attending a self-help group for family caregivers because he had cared for both his parents, who were affected by dementia—I phoned him a week later:

Tommaso: But they didn't they say anything to you? The virus has got into my mother's care facility.

FD: Oh, I'm sorry!

Tommaso: I told you that if the virus got in it would be like putting a bomb at the station . . . I don't know much because I haven't visited her for a month. I went on Tuesday after the first decree because I already understood the climate, but they didn't let me in—yes, very cordial and kind, but they didn't let me in. I heard about the virus from the manager, who called me; he told me there are three housekeepers at home on sick leave as a precaution, but I don't know if all three have the virus. The director says he is struggling to have everyone who works there get a swab, but they can't do it—it's only for those who have symptoms . . . Then an asymptomatic person will infect 50 people. [phone conversation; 22 April 2020]

Uncertainty and fuzziness about the future perpetuated the idea that the infection in residential care facilities would be a death sentence for many vulnerable older people. As I mentioned early, the flows of data and information about infections in residential-care facilities and the terrifying hypothesis that this contagion was intentionally driven by political administrations seemed to anticipate an apocalyptic future for the oldest members of the community. Some scholars interpreted it as a sign of a shameful society that is unable to take care of the oldest members of the community who live in conditions of abandonment and social isolation.⁸ The COVID-19 pandemic and its associated lockdown policies increased the perception of residential-care facilities as “cold” forms of care as opposed to the “warm” care provided by relatives, and as a sign of social death and family abandonment (Thelen 2015, 210). However, the discourses on warm family care reproduced an idealized vision of family relationships that was sometimes contested by my interlocutors. This was especially true for situations where the COVID-19 pandemic forced family members to rearrange the care provided to an older family member in an unwanted way. In an online meeting of the caregiver support group, Tommaso lashed out about the fatigue of living with his mother-in-law—she and her daughter (his ex-wife) had come to stay with him because the lockdown had interrupted the renovating work in their home:

A member of the group: You're so nice! You take care of both of them.

Tommaso: Ehm [*laughing*]. She is one of those who always complains about everything. My ex-wife has got no patience with her, so it's all up to me. She calls me all the time, but I've seen that she is able to do things alone when she has no one to rely on, so now I come only when I'm really needed. She is one of those aged people who always complains. Before this situation, we had applied to the adult-day care center for some relief but now everything has been stopped. [transcript from one online meeting of the caregiver support group; 29 April 2020]

In Italy, where the institutionalization of older adults has always been viewed as a betrayal of traditional family values (Degiuli 2010), the information about COVID-19 in residential-care facilities worsened the social blaming of family members with older loved ones living in these homes; e.g., the psychologist Lisa's words about the sense of guilt felt by her patients' relatives. In this sense, I consider the phone conversation that I had in early April 2020 with Elsa (age 74), a woman who attended the Café. Elsa was the sole caregiver for her husband, who was affected by dementia; she had also cared for her father at home until he died in March. But rather than describe the way she experienced the loss of her father in the pandemic, I want to briefly consider how this woman, who had decided a year ago to take care of her father at home instead of finding a residential-care facility, spoke about such facilities. We were discussing the situation regarding viral contagion in the residential-care facilities in the same town as the Alzheimer's Café; she told me that patients' relatives had been told that infected patients would be sent to a residential-care facility where an old friend of hers lived; one who she used to visit before the lockdown:

I've told her, "You know, I have a small room in my house; please come whenever you want." And that is because her daughter doesn't care about her. If she were my father, I would have brought him back home immediately. You see, Francesco, she is one of the 'modern women' and it is true that not everyone is like me: she doesn't want her around, she doesn't want to wash dishes and do the housework for her, and I suspect that even her boyfriend doesn't want her. She does not care." [phone conversation; 15 April 2020]

It seems that the COVID-19 pandemic exacerbated pre-existing social norms on senility and kin responsibility for care rather than radically altering them. These norms concerned the idea that older people were vulnerable and passive subjects during the pandemic, assuming that the relatives—especially the woman of the households—were primarily responsible for their health and wellbeing. The social construction of old age has not been shaped by the COVID-19 pandemic and lockdown itself; rather, it seems that interpretations of old age related to the socio-cultural context have shaped how the pandemic has been represented and conceived.

In the following section, I examine the interpretation of senility and family responsibility for care, as expressed through local idioms of fatigue and exhaustion in caring for a family member (Danely 2017). These emerged from the life story of a family caregiver who I interviewed in these early months of the pandemic.

Family Life and Fatigue: Adriana's Story

In April, I was concerned about Adriana, a retired schoolteacher who lives in the countryside with her husband, Viviano (age 55) who was diagnosed with early-onset Alzheimer's in 2016. Her son works in a nearby factory, and Adriana cares for her mother (age 90) who has lived with them since she became a widow and had both legs surgically amputated. I met Viviano and Adriana at the Café, but we did not speak much before the lockdown. However, she kindly accepted my request to interview her during the lockdown months; we made a sort of weekly appointment that was very close to the Café times. I phoned Adriana several times from the beginning of lockdown, usually in the morning, after she was done with care activities and when the home care-workers were taking care of Viviano and her mother, which left her some free time. Adriana had been one of the more active participants at the Café, and she often took the floor to talk about something that had happened recently: an event, a new problem, or new anxieties and worries. But, like many others, she seemed to struggle a lot to speak about her present situation, the relationship with her husband and her mother, and the way her husband behaved at

home. Nevertheless, she appeared to be endowed with patience and the capacity to endure. At the Café, she used to smile a lot and reflect on her sorrows with a huge sense of self-irony and humour. Two years after the diagnosis of Viviano's early-onset dementia, it had taken several months for Adriana to be able to speak with other people about her husband's situation. Little by little, thanks also to her gynecologist who begged her to look for help "because these sorrows are too heavy to be carried by a single person," and to her psychologist who said, "Mrs., you don't need a psychologist: instead, you need to find other people who are living the same experiences," she started to look for a support group which have been recently multiplying in Italy. She initially refused the idea of bringing her husband to an Alzheimer's Café, partly because her family doctor believed that Viviano was still young and that an "old" environment such as the Café would not be a positive thing. But when his symptoms became worse, she finally decided to come to the Café, where we met in November 2019.

Similar to my other research informants, I often asked myself if my interviews would cause Adriana suffering; if our discussions might touch on intimate and sensitive aspects of her past and present that could harm her—something she would be unwilling to speak or hear about. Some others had refused to speak with me because they believed that the present was too heavy to be mentioned or thought about. But Adriana often confessed to me that she appreciated our phone conversations; she felt they were good for her because the Café had been closed. She had lost a place that she couldn't do elsewhere; a place where she could speak about her situation and being listened to. Viviano had been a skilled mechanic who used to say that he needed to use his brain for his work, not only his hands. Two years after the diagnosis of dementia, his condition worsened, and Adriana had to leave her job as a teacher to care for him. Although he has seven brothers and sisters, they didn't really care for him after the illness started—something that Adriana regretted but that she also made sense of through a disenchanted view of family relationships, saying with a bitter smile: "He was very much there for his sisters and brothers when they were in need. I can say that they haven't returned this attention, but I know that it often goes like that; this is how things go." After the illness started, all of her husband's friends almost entirely disappeared, including his former colleagues:

They always ask me or my son how Viviano is doing. I always respond: "Why don't you come round? Even for a short visit—spend some time with him, he would appreciate it." But they never come. They say that they can't stand seeing him like that; they suffer too much. I understand that it's hard, but I also understand that he feels lonely because of that. [phone conversation; 9 April 2020]

Her son has never accepted his father's illness and refused to speak about it. Adriana confessed to me that she always wondered whether maybe the illness would have been less aggressive if her son—who shared Viviano's passion for motorcycles—had spent more time with his father; for example, taking him to motorbike races. For this reason, she cannot rely on him much, "because he has no patience; he is very rude with him when he forgets something, and then he [Viviano] suffers a lot." She also told me that the son used to say to both his grandmother and his father, "When mom can't stand any more, I'll put both of you away! [in a nursing home]."

Adriana and Viviano didn't have a very "active" social life, which was similar to many older members of the Alzheimer's Café, who often mentioned how friends and relatives usually disappear after the illness starts. The Café allowed members to remake social and family ties. Many members also used to meet outside the Café' scheduled meetings, going out for dinner all together with the psychologist Lisa and her husband. For this reason, many of them referred to the Café as a "new family."

In the conversation we had, Adriana and I talked a lot about the pandemic. She believed that she was luckier than people living in the city (she lived in the countryside) because she was able to go into the garden with Viviano and take a walk in the small woods nearby, as they had usually done. Viviano spent the lockdown months working in the small garden outside. Adriana often talked about the image of her husband crying with his hands on his face because he failed to dress himself in the morning, or because he realized he could not recognize the home repairs he was once able to do:

There are good days and less good days. For example, a few days ago it was Viviano's birthday. Before lunch I had told him to make fruit salad with my mother. While he was cutting an apple, my mother said to him: "Why didn't you peel it?" He got angry, threw the apple on the table, and went to the bedroom. I found him on the bed crying with his hands on his face. In these cases, he closes in on himself more than usual. [phone conversation; 9 April 2020]

On one of the "good days," Adriana told me with enthusiasm and happiness that Viviano smiled when he saw Lisa—the psychologist at the Café—speaking on television, and she got the impression that her husband's personhood was still there in some way.

On these days, she struggled with the decision of whether or not to suspend the home care worker, being caught in the middle of the care needed by her husband and the care needed by her mum while getting no help from her son:

I've been wondering for a long time if I was right to get the home care worker [*assistente familiare*] to help me out. I also talked about it with the family doctor, because my neighbors who have vulnerable relatives have suspended all contacts because they are afraid, and I too am afraid. [phone conversation; 16 April]

For example, Adriana's neighbor, whose husband has only one lung, suspended the family assistant who came every day. Adriana told me: "And then I asked myself, 'But can I do it alone with my husband and mother?' And so, in the end, I put the weights on the scale and decided."

Just before the pandemic, she had made another important decision for her and Viviano: through the social service, she contacted an adult-day care center, which people attend from the morning to the afternoon every day or certain days per week. There, they engage in socialization activities, memory exercises, and psychosocial therapy, and family members receive some respite moments. Adriana tried to justify that decision on a dual basis. First of all, she believed that she needed to take some time for herself and engage in other activities because she had to give up work prematurely to care for Viviano. Second, it was because she thought her husband needed to adapt to other caregivers in case something bad happened to her. She was happy that her husband seemed to have accepted the decision: "He didn't jump for joy, but he didn't say anything bad either." But then the lockdown came, and the adult day-care center was shut down just when she had begun the process to activate the service for her husband. One afternoon at the end of April, for the first time, it was she who phoned me:

It is not that we used to go out a lot, but we used to do little things such as going for a car ride. At one time, his crises were rare but now, I see that they are frequent and he looks absent most of the day. This morning was very hard: he tried to dress himself alone; he realized he was not able to do it anymore, and then began to cry with his head in his hands. Now he is with the *assistente familiare* [home care worker]: she was very good; she handled the situation by getting him to do some work in the garden. Maybe

I will go for a car ride again. I want to speak with Lisa—to ask her if it is a good idea, and if she has some advice because I miss the discussions at the Café. Thanks for your calls; it really helps me to talk about my situation with other people. Do you think I can call Lisa? I don't want to look for another psychologist because I would have to start again telling our story from the beginning, and it's a real struggle [*laughing nervously*]. [phone conversation; 24 April 2020]

I phoned her a week after that conversation to hear how she was handling the situation. I found her, surprisingly, more relaxed. She told me that she had cried over the weekend but then found in herself the strength to go on and endure. I noticed from her tone of voice that she was smiling bitterly when she admitted that: “Also, because what should I do? I don't see any other alternatives; I HAVE to go on and endure, and try to have hope and see the positive side.”

Adriana's tales of fatigue and daily struggles during the pandemic were not so different from how they were before it, and like many other interlocutors, she believed that COVID-19 didn't radically affect her social life. Even though her son, who worked in a car-parts factory, was forced to stay at home during the pandemic, it had not changed the situation—Adriana still had to assume all the responsibility for care, including making important life-decisions alone, such as whether or not to suspend the home-care worker because she was unable to care for both her husband and her mother.

Conclusion

What happened to old age and caregiving during the first period of COVID-19 pandemic? Has the COVID-19 pandemic radically altered the way we understand fundamental notions of aging, care and family relations? In this article, I have presented representations of aging and caregiving fatigue that emerged during the pandemic in Italy between February and May 2020. Considering pandemic, lockdown, and social isolation with respect to pre-existing global ideas and normative models about senility, individual autonomy, and caregiving (Lamb 2017, xi-xv; Cohen 1995), I have examined a representation of the “burden” of old age that shaped the Italian media's portrait of the vulnerable older people and their exhausted caregivers; I then juxtaposed this representation with the narratives of daily struggles from family caregivers and the members of a local Alzheimer's Café, including the psychologist. The viral contagion in residential-care facilities increased the stigma and mistrust of these institutions as places of family abandonment and social isolation in contrast with the “warm” domestic environment (Thelen 2015, 210; Visser 2019). Information about infections increases anxiety not only among residents of these facilities, as some scholar noticed (Schroyer 2021), but also among their relatives, popularly accused to betray traditional family values to care for older people at home.

Finally, I have also presented the life story of a family caregiver during the pandemic in order to critique the idealized vision of family care that went alongside the promotion of home-care in Italy—a vision containing structural and gender inequalities that have been reproduced under the pandemic (Degiuli 2010). In Adriana's story, social isolation came long before the pandemic, which had not changed the way the responsibility for care was arranged in her family and household: it was she and the home-care worker who performed all of the care activities.

This is not to say that the COVID-19 pandemic has not been a radical event with serious long-term consequences. The suspension of public and private home-care services, as well as semi-residential services such as adult day-care centers, increased social inequalities and posed serious threats to older people and their family in Italy and elsewhere (Kent *et al.* 2020; Manderson and Levine 2020). And yet, before the COVID-19 pandemic in Italy, like many places in the so-called Euro-American area, the

general assumption had been that modern medical technologies have succeeded in defeating the infectious diseases of the past, and have given us the opportunity to live a long life. The issue has thus become finding ways to face the ironic consequences of having achieved longevity—namely, chronic illnesses and mental disabilities, and the threats that they pose to family and community life (Cohen 1995, 316-319; Sivaramakrishnan 2018). The consequences of COVID-19 were related to pre-existing structural holes in the care system, making even more visible all of the care labour that is needed not only to make long life possible but also to improve the quality of life in several illnesses such as dementia. Sustaining this care labour includes the necessity to fight against the taboo, social isolation, and blaming that surround who live with the diseases and their family networks. In this sense, the pandemic and the lockdown reflected pre-existing cultural interpretations and normative models about old age and kin responsibility for care rather than radically altering them. The social construction of old age has not been shaped by the pandemic and lockdown itself: rather, it seems that interpretations of old age and caregiving related to the socio-cultural context have shaped how care for older people has been represented and managed during the pandemic.

Notes

1. All the names have been changed.
2. All the interviews and newspaper articles have been translated from Italian by the author.
3. Latour, Bruno. 2020 “Is This a Dress Rehearsal?”. *2020 Pandemic*, Critical Inquiry blog. March 26. Accessed June 12, 2020. <https://critinq.wordpress.com/2020/03/26/is-this-a-dress-rehearsal/>.
4. Curare Editorial Team. 2020 “Curare Corona Diaries Project. Call for Diaries in the Strict Sense of the Term”. *Witnessing Corona*, Boasblog. March 23. Accessed June 10, 2020. <https://boasblogs.org/witnessingcorona/curare-corona-diaries-project/>.
5. Irons, Rebecca. 2020. “Grasping for Unity in a Divided Britain: Ageism, Brexit-Era Politics and the Covid-19 ‘Boomer Remover’”. *Consciously Quarantined: A Covid-19 response from the Social Sciences*, UCL Medical Anthropology blog. March 24. Accessed June 9, 2020. <https://medanthucl.com/2020/03/24/grasping-for-unity-in-a-divided-britain-ageism-brexite-era-politics-the-covid-19-boomer-remover/>.
6. Danelly, Jason. 2020. “Those Who Come Early: Reflections on the Social Standing of Senior Citizens in the Time of Covid-19 Pandemic In Japan”. *The Age of Covid-19*, Somatosphere blog. May 31. Accessed June 13, 2020. <http://somatosphere.net/2020/those-who-come-early.html/>.
7. I omitted the source to protect the anonymity of my informants.
8. Douglas, Cristina. 2020. “Lives and Deaths with Dementia DURING Covid-19: Our Shameful (but Hopeful Transformative) Post-Pandemic Legacy.” *Co-existing with Covid-19: Moving into the post-pandemic world with the social sciences*, UCL Medical Anthropology Blog. June 12. Accessed June 20, 2020. https://medanthucl.com/2020/06/12/lives-and-deaths-with-dementia-during-covid-19-our-shameful-but-hopefully-transformative-post-pandemic-legacy/?fbclid=IwAR0qBcgW_rSnhyysRzX_JXUywZHPyJxvXMf67jBgN6wfXjzfNqmVmEXYCoI.

References

- Ascoli, Ugo, and Emmanuele Pavolini. 2010. “Le due Italie del welfare locale: le conseguenze di decentramento e regionalizzazione in assenza di regia nazionale.” *Il Mulino* 2: 99-109.
- Allen, Laura D., and Liat Ayalon. 2021. “ ‘It’s Pure Panic’: The Portrayal of Residential Care in American Newspapers During COVID-19.” *The Gerontologist* 61 (1): 86-97.
- Bertossi, Erika. 2020. “Covid-19 e anziani. La psicologa spiega a chi si prende cura di loro come gestire la quarantena,” *BolognaToday*. May 2. Accessed June 12. <http://www.bolognatoday.it/cronaca/coronavirus-anziani-conseguenze-caregiver-regole.html>.

- Bifulco, Lavina with Massimo Bricocoli and Raffaele Monteleone. 2008. "Activation and Local Welfare in Italy: Trends and Issues." *Social Policy and Administration* 42 (2): 143-159. doi: 10.1111/j.1467-9515.2007.00600.x.
- Bricco, Paolo. 2020. "Quell'Italia dei nonni e del boom demografico sarà spazzata via dal coronavirus." *Il Sole 24ore*. April 5. Accessed June 15. https://24plus.ilsole24ore.com/art/InchiestaAnziani_Bricco-ADxKwJH?fbclid=IwAR2Fk2OxomCJLmyKFOo7lfr6L9WPoEErmSxxdoOlrPkO8-VKcklKK3cfU7Y.
- Cohen, Lawrence. 1995. "Toward an Anthropology of Senility: Anger, Weakness and Alzheimer's in Banaras, India." *Medical Anthropology Quarterly* 9 (3): 314-334.
- Cohen, Steven A., with Zachary J. Kunicki, Megan M. Drohan, and Mary L. Greaney. 2021. "Exploring Changes in Caregiver Burden and Caregiving Intensity Due to COVID-19." *Gerontology and Geriatric Medicine*, January 2021.
- Danely, Jason. 2015. "Of Technoscapes and Elderscapes. Editor's Commentary on the Special Issue 'Aging the Technoscape.'" *Anthropology and Aging* 36 (2): 110-111. doi:10.5195/aa.2015.121.
- Danely, Jason. 2017. "Caregiver Narratives of Fatigue and Endurance in Japan and England." *Subjectivities* 10: 411-426. doi: 10.1057/s41286-017-0037-7.
- Degiuli, Francesca. 2010. "The Burden of Long-Term Care: How Italian Family Care-Givers Become Employers." *Ageing and Society* 30: 755-777. doi :10.1017/S0144686X10000073.
- Di Todaro, Fabio. 2020. "Coronavirus: le difficoltà di malati e caregivers durante l'isolamento." *La Stampa*. April 29. Accessed June 20, 2020. <https://www.lastampa.it/salute/2020/04/29/news/coronavirus-le-difficolta-dei-malati-e-dei-caregiver-durante-l-isolamento-1.38745276>.
- Dubois, S. Maria. 2020. "Coronavirus, lo psicologo: come parlare ad anziani e bambini." *Il Corriere della Sera*. February 26. Accessed October 10, 2020. https://corrieredelveneto.corriere.it/veneto/cronaca/20_febbraio_26/coronavirus-psicologo-come-parlare-ad-anziani-bambini-d8257dc6-586f-11ea-8ac8-f5da3705b70d.shtml
- Fabretto, Madina. 2020. "Coronavirus: perché è più pericoloso per gli anziani e cosa è meglio fare." *La Difesa*. March 16. Accessed October 10, 2020. <https://www.difesapopolo.it/Media/OpenMagazine/Il-giornale-della-settimana/ARTICOLI-IN-ARRIVO/Coronavirus-perche-e-piu-pericoloso-per-gli-anziani-e-cosa-e-meglio-fare>.
- Gulia, Abhity, Seema Mishra, and Sushma Bhatnagar. 2020. "Multiple Caregiving Role with the Novel Challenge of COVID-19 Pandemic: A Crisis Situation." *Indian Journal of Palliative Care* 26 (1): 163-65.
- Greenberg, Jessica, and Andrea Muehelebach. 2007. "The Old World and its New Economy: Notes on the "Third Age" in Western Europe." In *Generations and Globalization: Youth, Age, and Family in the New World Economy*. Edited by Jennifer Cole and Debora Durham, 190-215. Bloomington: Indiana University Press.
- Kaplan, Matthew, Mariano Sanchez, and Leah Bradley. 2015. "Conceptual Frameworks and Practical Applications to Connect Generations in the Technoscape." *Anthropology and Aging* 36 (2): 182-204. doi: 10.5195/aa.2015.99.
- Kent, Erin E., Katherine A. Ornstein, and Nicholas J. Dionne-Odom. 2020. "The Family Caregiving Crisis Meets an Actual Pandemic." *Journal of Pain and Symptom Management* 60 (1): 66-69.
- Lamb, Sarah, ed. 2017. *Successful Aging as a Contemporary Obsession: Global Perspectives*. New Brunswick: Rutgers University Press.
- Leibing, Annette. 2017. "Successful Selves? Heroic Tales of Alzheimer's Disease and Personhood in Brasil." In *Successful Aging as a Contemporary Obsession: Global Perspectives*. Edited by Sarah Lamb, 203-218. New Brunswick: Rutgers University Press.
- Marrone, Cristiana. 2020. "Cosa sappiamo sulle morti legate al Coronavirus in Italia." *Il Corriere della Sera*. February 24. Accessed October 10, 2021. https://www.corriere.it/salute/malattie_infettive/20_febbraio_24/coronavirus-vittime-sono-davvero-morte-covid-19-7b733736-56e8-11ea-b89d-a5ca249e9e1e.shtml

- Manderson, Lenore, and Susan Levine. 2020. "Aging, Care, and Isolation in the Time of COVID-19." *Anthropology & Aging* 41 (2): 132–40.
- Nedelcu, Mihaela, and Malika Wyss. 2016. "'Doing Family' Through Ict-Mediated Ordinary Co-Presence: Transnational Communication Practices Of Romanian Migrants in Switzerland." *Global Network* 16 (2): 202-218.
- Pavolini, Emanuele, and Costanzo Ranci. 2008. "Restructuring the Welfare State: Reforms in Long-Term Care in Western European Countries." *Journal of European Social Policy* 18(3): 246–259.
- Pavolini, Emanuele. 2015. "Welfare all'Emiliana (la famiglia e i servizi)". *Il Mulino* 1: 125-130.
- Pavolini, Emmanuele and Elena Spina. 2015. "Users' Involvement in the Italian Nhs: The Role of Associations and Self-Help Groups." *Journal of Health Organization and Management* 29 (5): 570-581, doi: 10.1108/JHOM-05-2014-0089.
- Peletz, Michael. 2000. "Ambivalence in Kinship the 1940s." In *Relative Values: Reconfiguring Kinship Studies*. Edited by Sarah Franklin and Susan McKinnon, 413–44. Durham (USA): Duke University Press.
- Previtali, Federica, with Laura D. Allen, and Maria Varlamova. 2020. "Not Only Virus Spread: The Diffusion of Ageism during the Outbreak of COVID-19." *Journal of Aging & Social Policy* 32 (4–5): 506–14.
- Rickly, Francesca. 2020. "Old, disabled, successful? Transfigurations of aging with disabilities in Switzerland." *Medicine Anthropology Theory* 7 (1): 117–135. doi: 10.17157/mat.7.1.630.
- Reynolds, Laurinda. 2020. "The COVID-19 Pandemic Exposes Limited Understanding of Ageism." *Journal of Aging & Social Policy* 32 (4–5): 499–505.
- Sadler, Euan, and Christopher McKeivitt. 2013. "'Expert Caregivers': An Emergent Normative Model of the Caregiver." *Social Theory & Health* 11 (1): 40-58. doi:10.1057/sth.2012.17.
- Schroyer, David. 2021. "Media Effects on Individual Worldview and Wellness for Long-Term Care Residents Amid the COVID-19 Virus." *The Gerontologist* 61 (1): 8–12.
- Sivaramakrishnan, Kavita. 2018. *As the World Ages. Rethinking a Demographic Crisis*. Cambridge (USA): Harvard University Press.
- Thelen, Tatjana. 2015. "Care as Social Organization. Creating, Maintaining and Dissolving Significant Relations." *Anthropological Theory* 15 (4): 497-515.
- Verbruggen, Christine, Brittney M. Howell, and Simmons Kaylee. 2020. "How We Talk About Aging During a Global Pandemic Matters: On Ageist Othering and Aging 'Others' Talking Back." *Anthropology & Aging* 41 (2): 230–45.
- Visser, Renske. 2019. "Going Beyond the Dwelling: Challenging the Meaning of Home at the End of Life." *Anthropology and Aging* 48 (1): 5-10. doi: 10.5195/aa.2019.215.