



DOSSIÊ: CUIDADO E EMOÇÕES: DISCURSOS, PRÁTICAS E EXPERIÊNCIAS

## The political work of emotions: care, pandemic, and protest in Spain

*O trabalho político das emoções: cuidados, pandemia e protesto na Espanha*

*El trabajo político de las emociones: cuidado, pandemia y protesta en España*

**Raúl Márquez Porras<sup>1</sup>**

[orcid.org/0000-0002-2765-1845](https://orcid.org/0000-0002-2765-1845)  
[raulmarquez@ub.edu](mailto:raulmarquez@ub.edu)

**Sílvia Bofill-Poch<sup>1</sup>**

[orcid.org/0000-0001-7887-841X](https://orcid.org/0000-0001-7887-841X)  
[bofill@ub.edu](mailto:bofill@ub.edu)

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**Abstract:** We analyse the impact of the pandemic on the care system in Spain. In particular, we focus on the perspective of relatives to illuminate the crisis of the residential care model that the Covid-19 pandemic brought to light. The pandemic had a major impact on Spanish care homes, with one of the highest mortality rates in the European Union. This caused suffering, not only for residents, but also for relatives, who reacted by mobilising and demanding political accountability. In line with the anthropology of emotions, we analyse the *emotional grammars* underlying the protest to show how the suffering of relatives becomes intelligible in the framework of a residential care model in crisis, and how it acquires political value beyond the private and individual sphere in which care is usually understood. Thus, we show the political work of emotions and their analytical potential in examining the transformations and challenges of the current care system.

**Keywords:** Care homes. Covid-19. Protest. Emotions. Dignity.

**Resumo:** Este artigo analisa como a pandemia impactou o sistema de cuidado na Espanha. Toma como elemento central de análise a crise do modelo residencial que a pandemia trouxe à tona e o faz a partir da perspectiva dos familiares. A pandemia teve um grande impacto nas casas de idosos, com uma das maiores taxas de mortalidade da União Europeia. Isso causou sofrimento, não apenas entre os residentes, mas também entre os familiares, que reagiram mobilizando-se e exigindo responsabilidade pelo que aconteceu. Em consonância com a antropologia das emoções, o objetivo é analisar as *gramáticas emocionais* subjacentes ao protesto, para mostrar como o sofrimento dos familiares se torna inteligível na estrutura de um modelo de cuidado residencial em crise e como ele adquire valor político além da esfera privada e individual na qual o cuidado é normalmente pensado.

**Palavras-chave:** Casas de idosos. Covid-19. Protesto. Emoções. Dignidade.

**Resumen:** El artículo analiza la forma como la pandemia impactó el sistema de cuidados en España. Toma como elemento central de análisis la crisis del modelo residencial que la pandemia evidenció y lo hace desde la perspectiva de los familiares. La pandemia tuvo un impacto importante en las residencias, con uno de los índices de mortalidad más elevados de la Unión Europea. Ello provocó sufrimiento, no solo en los residentes, sino también en los familiares, quienes reaccionaron movilizándose y exigiendo responsabilidades por lo acontecido. En línea con la antropología de las emociones, se trata de analizar las *gramáticas emocionales* que subyacen a la protesta, para mostrar cómo el sufrimiento de los familiares se torna inteligible en el marco de un modelo de atención residencial en crisis, y como adquire valor político más allá del ámbito privado e individual en el que suele pensarse el cuidado.

**Palabras clave:** Residencias. Covid-19. Protesta. Emociones. Dignidad.



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<sup>1</sup> Universitat de Barcelona (UB), Barcelona, Espanha.

## Introduction

The Covid-19 pandemic had a major impact on care homes for older adults in Spain, with one of the highest mortality rates in the European Union (Comas-d'Argemir and Bofill-Poch 2022). This caused suffering, not only for the residents, but also for their relatives, who reacted by mobilising and demanding accountability. In this article we take this suffering as a social fact to show how it becomes intelligible within the framework of a model of long-term care that does not meet the needs of older people. We show how this suffering acquires political value beyond the private and individual sphere in which care is usually thought of. In line with the anthropology of emotions, we analyse the *emotional grammars* underlying the protest of the relatives of care home residents in the context of public long-term care policies (Coelho and Beleli 2022). We focus on the process of politicisation of pain that occurs through collective action (Pita 2010), highlighting the political work of emotions (Goodwin, Jasper and Polletta 2001; Durão and Coelho 2012; Coelho and Durão 2017). We also focus on how relatives contested the legitimacy of health policies that prioritised a biomedical model of care over a social model, showing the counterproductive effects that such policies had on the well-being of residents and relatives. Here, we take up the notion of the *moral economy of life* proposed by Didier Fassin (2021), in order to better understand this process of politicisation of grief, death, and care promoted by relatives. With this article we contribute to the discussion on the analytical potential of emotions in sustaining and transforming care systems, with an emphasis on the articulation between orders of morality, care home models, and processes of politicisation.

## Methods

In this article we present part of the results of a larger research project on the impact of the pandemic on the social care sector in Spain.<sup>2</sup> The research covered the analysis of different sectors: family care, home care services, personal assistance, domestic employment, and care homes. To this end, we carried out fieldwork consisting of 343 in-depth interviews with workers, service managers, family members, trade unions, employers, politicians, and other experts. We also consulted statistical sources and documents published by official organisms on the impact of the pandemic on the sector. In writing this article, we rely exclusively on the results of the analysis of the care home sector, for which 115 in-depth interviews were conducted with the various actors mentioned above. More specifically, we present the results of the interviews conducted with relatives of older residents, mainly daughters, during the period from July 2020 to July 2023. In total we conducted 22 interviews with members of the most significant care home relatives' associations and platforms in Catalonia (Coordinadora de Residencias 5+1, Plataforma Afectados por Coronavirus), Madrid (Marea de Residencias, Asociación por los Derechos de los Mayores y sus familiares-Ademaf) and the Basque Country (Babestu, Irauli Zaintza, Pentsionistak Martxan) and members of smaller groups of relatives in Madrid and Catalonia. In addition, we consulted reports and documents produced by these and other platforms, such as the Plataforma por la Dignidad de las Personas Mayores en Residencias-Pladigmare or the Plataforma Estatal de Familiares de Familiares de Usuarías de Residencias (La Plataforma). Due to the pandemic-related health concerns, most of the interviews were conducted by videoconference. The names of the participants have been anonymised.

<sup>2</sup> Cumade: *Care matters. Gender impact on caregivers of elderly and dependent persons in times of Covid-19 (2020-2021)*, led by Dolors Comas-d'Argemir from the Universitat Rovira i Virgili, funded by the Fondo Supera Covid-19 Santander-CSIC-Crue; and Caremodel: *The model of long-term care in transition: political, family and community strategies to face the consequences of the Covid-19 pandemic (2021-2024)*, led by Montserrat Soronellas and Yolanda Bodoque from the Universitat Rovira i Virgili, funded by the Spanish Ministry of Science and Innovation IMCIN/AEI-PID2020-11487RB-31.

### The crisis of care homes in Spain: a neglected sector<sup>3</sup>

One year after the state of alarm was declared in Spain (in March 2020), just over 30,000 people had died in care homes due to Covid-19 or compatible symptoms (according to data from Imsero, the Institute for Older Adults and Social Services). This represents 41.7% of all deaths from Covid-19 in that period.<sup>4</sup> Spain was not the only country to suffer the impact of the pandemic in care homes, but it was one of the European Union countries that suffered the most virulently (Comas-Herrera et al. 2020). This higher incidence is not due to a single cause, but to a combination of factors.

The reports and research published to date have identified factors related to the current situation, including lack of knowledge of the virus, lack of diagnostic tests, lack of protective equipment, confusion in the face of protocols that varied from day to day, asymptomatic cases that went unnoticed, overcrowded spaces, and problems of coordination with the health system (del Pino et al. 2020). Structural factors related to the care home sector should be added here, such as underfunding of the sector, lack of infrastructure, insufficient staffing levels, and job insecurity (Montserrat 2020; Costa-Font, Jiménez and Viola 2021). Undoubtedly, budget cuts and the lack of investment in the sector for more than a decade made it difficult for care homes to respond more effectively to the effects of the pandemic.

Sociologist Mary Daly (2020), in her analysis of the impact of the pandemic in the United Kingdom and the European Union, argues that in addition to structural factors—such as those mentioned above—there were political and socio-cultural factors related to the lack of recognition of social care. In the case of Spain, this meant that the System for Autonomy and Care for Dependency (Saad, the national system created in 2007 to meet the needs of people with a dependency) was subordinated to the guidelines of the National

Health Service (SNS). The guidelines issued by the national health agency, which led the fight against the pandemic, changed frequently and were insensitive to the characteristics of care homes, showing a lack of knowledge of the residential context. In this light, it was decided, for example, to isolate people in their rooms and prohibit family visits to prevent the spread of the virus. In practice, care homes became total institutions (Goffman 1961), denying residents and family members any decision-making capacity and autonomy.

In any case, the pandemic has exacerbated shortcomings that already existed beforehand. Spain's model of residential care is an obsolete system that does not respond to the real needs of citizens. The care home is a place where people do not want to go and which does not serve the purposes for which it was developed: The users are increasingly older and have multi-pathology conditions that require much more specialised care and a much larger workforce. In terms of working conditions, the residential care sector is characterised by precariousness and lack of professionalisation. Care homes are under-staffed, with temporary and part-time contracts. Eighty percent of jobs are part-time. Eighty per cent of jobs are in the lowest categories (e.g., geriatric care workers or cleaning and catering workers), which correspond to low salaries. According to data from the Labour Force Survey, 91.9% of the workers are women. In the context of the pandemic, the overload of tasks, the lengthening of working hours, and the risk of contagion became generalised among all workers, to the detriment of their working conditions and the quality of the care they provided.

On the other hand, the residential care system is heavily privatised. In Spain (according to Imsero, 2020), there are 5,542 care homes with some 389,031 beds available to care for older people. Most care homes (74.1%) are privately

<sup>3</sup> The information used for writing this section comes from the report: Comas-d'Argemir and Bofill-Poch (eds.) (2021). *El cuidado importa. Impacto de género en las cuidadoras/es de mayores y dependientes en tiempos de la Covid-19*. Fondo Supera Covid-19 Santander-CSIC-CRUE, particularly Chapter 4: "Residencias, las grandes olvidadas", coordinated by Dolors Comas-d'Argemir, Matxalen Legarreta-Iza and Cristina García.

<sup>4</sup> Imsero, Informe semanal Covid-19 en Centros Residenciales. Actualización 4.

owned, managed by commercial companies or, to a lesser extent, third sector organisations (many of which belong to religious orders). However, the majority of beds (62.3%) are publicly subsidised. In addition, the majority of public care homes (25.9% of the total) are managed by private companies. The injection of public money has facilitated their expansion and has been an incentive for multinational companies and investment funds to enter the sector, seeing it as a niche for profit. It is therefore a model that serves the profit-making purposes of large business groups (expanding in the sector) but is unsatisfactory for the care needs of older people and people with disabilities.

During the height of the pandemic, the healthcare system collapsed, and care home care was side-lined. Hospital referral for care home residents was restricted, and people who could have continued to live were left to die.<sup>5</sup> In short, there was an obvious lack of attention on the part of the public authorities. Although care homes were listed in official documents as "essential service operators", they were politically and epidemiologically ignored at the onset of the pandemic. We analyse the impact of the pandemic on care homes from the perspective of family members, who reacted by organising civil associations and platforms to denounce the effects of abandonment and neglect on their relatives.

### **Guilt, grief and anger: the suffering of relatives**

The measures dictated by the health authorities caused suffering among the residents and their relatives. They experienced guilt, grief, and anger stemming from the ban on visits; poor communication; lack of transparency; uncertainty; the isolation and confinement of residents; the interruption of physical, sensory and cognitive stimulation programmes; and the management of pre-mortem and post-mortem situations (deceased persons who remained for days in their rooms

due to lack of assistance from funeral homes).

Relatives felt guilt for having taken their family member to the care home and for not being able to get them out when the pandemic broke out. During the pandemic, very few relatives managed to get their family member out of a centre; most did not have that option, even though they knew it was not a "safe" place. This sense of guilt makes perfect sense within a family-based model of care, in which the family, and women in particular, are ultimately responsible for the care of older members. In general, older people are taken into care home when caring at home is no longer viable. This usually produces a moral conflict that can be related to a conception of caring at home as a still-predominant cultural ideal (Comas-d'Argemir and Soronellas 2019; Bofill-Poch 2018). The multiple pathologies that older people often have require adapted care homes and professionalised care that cannot be provided at home, as well as time and availability for care. The pandemic revives, in a sense, the moral dilemma of the caregiver, who feels a duty to provide care at home, but at the same time is unable to do so. In a sense, it revives the feeling of family surrender that many relatives feel when it is time to take the relative to the care home. This is described as an extreme, heart-breaking situation in which they never imagined they would find themselves.

Marta, for example, whose mother-in-law was in a care home when the pandemic broke out, describes it as an inhumane situation: "You know that it's not a good place, that she's not going to be well cared for, that she could die at any moment, and even still, you have no choice but to keep her admitted". Cristina, who had just taken her husband to a care home, expressed something similar, using an unequivocal metaphor: "You know you are taking him to the slaughterhouse, but you have to do it".

The prohibition of visits produced a feeling of loss, of an abrupt interruption of the care relationship, which was painful.

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<sup>5</sup> There is evidence from two documents. First, the protocol issued by the Health Department of the Community of Madrid established as a criterion for exclusion from hospital referral a certain degree of dependency and other pathologies, which is common in older care home residents. Second, the protocol approved by the Emergency Medical System (SEM) of Catalonia in March 2020h established age as a screening criterion and spoke of "limiting the therapeutic effort" with people over 80 years of age (Comas-d'Argemir, Legarreta-Iza and Garcia 2021: 277-279).

Before the pandemic we went every day to give her dinner, so that she would continue to have a relationship with us, so that she wouldn't forget us, and suddenly, we were never able to go see her, only phone calls. All communication was digital. It makes you feel very sad, because you can't even hold her hand, you can't touch her, get close... She didn't understand anything that was happening. What made us panic is not being able to say goodbye to her. The moment may come and you won't even be able to hold her hand in the final goodbye. This is horrible, a tremendous hole-in-the-stomach feeling. They are such wild situations. That your mother is in the care home and that you cannot touch her, that you cannot hug her, that you cannot go see her, is inexplicable. (Marta, daughter-in-law, Association of Family Caregivers).

The anguish of the relatives increased as they learned of the precarious situation that existed within the care homes. Clara, whose father was in a care home, recalled those days: "You get that feeling inside and you say: 'What are they doing, how are they doing it...'. I prayed that they wouldn't phone me. Every time they phoned me I jumped. Uncertainty".

In relation to the management of the centres, relatives highlighted the misinformation about deaths. The lack of communication with the centres aggravated their pain and anguish. In most care homes, the management team sent an email or made a single call each day, prohibiting families from initiating contact. Direct communication with families took a few weeks from the start of the pandemic to activate in most cases and was limited to one or two video calls per week. The opacity outraged families and produced fear and uncertainty, as Lola expressed, "When I heard the news on TV [about the deaths in care homes], I was desperate. I got tired of crying at work. A day would pass and you would say: 'One more day has passed'. I had anxiety attacks, panic attacks. Panic that my mother would get infected and not be able to say goodbye". The way the deaths were reported to families was irritating. In extreme cases, all during the first wave, the deaths were reported abruptly, after days of silence, or the

funeral home itself was responsible for doing so.

It was especially painful not to be able to accompany a parent through illness and say goodbye in case of death. Gemma, whose father died during the first wave, highlighted some of the elements that caused that pain: "He died, and I couldn't touch him. They didn't let me touch him! I was dressed from top to bottom, with the protective gear, the gloves... They didn't even let me hold his hands with gloves on! Not even put my hand on his chest, he was suffocating!"

Beyond the 'policy' of communication and management of deaths, families criticised the unilateralism and lack of dialogue when taking restrictive measures. Starting with the first stay-at-home order, in March 2020, they highlight that the centres suddenly went into lockdown, from one day to the next and without allowing families to say goodbye. Given that schools and businesses were also being closed, the lockdown of care homes wasn't surprising. However, it was not expected to last for several weeks.<sup>6</sup> As the days went by, anger grew, as the lockdown continued even as the first wave of the virus came more or less under control. Families talked about "kidnapping" and used terms such as "prison": "They are sentenced to prison without [having committed] any crime"; "It has been a prison for them"; "We were locked up, imprisoned, punished, closed in...". They felt it was "torture" that the residents did not receive adequate care due to understaffing and poor conditions. This is how Clara expressed herself:

Now they say they protect them. And locking them in their rooms without being able to leave is called protection? Do they call it protection when not feeding them properly? Not cleaning them properly? Not giving them love or understanding or mobility properly? Keeping them as prisoners? Is this protection? (Clara, daughter, Marea de Residencias)

When we go to visit, we do not go through the care home, [the doors are] all closed. You are taken around back, through a garage, and there they set

<sup>6</sup> Depending on the region, the lockdown schedule varied, as it was the phase of the pandemic that defined whether or not visits could be authorised. In any case, the measures were not relaxed across the board until the vaccination process began at the end of December 2020 (Comas-d'Argemir, Legarreta-Iza and Garcia, 2021, 305).

up a space as if you were a contaminating weirdo. There are two tables set very far apart, and you are supposed to sit at one end. My mother sleeps and cries and then she leaves. It is total lack of communication. (Soledad, daughter, Marea de Residencias).

On many occasions, relatives relate that the long-awaited visit later generated frustration and sadness, both in the families and in the residents: "After visiting her father, my wife left him lying there. She was devastated", explained Joseba from the Iraulí Zaintza Platform. Aware of this, families repeated the phrase, "Either they die of grief, or they die of Covid." As the weeks and months passed, outrage grew.

Relatives spoke of violated dignity, undignified and undeserved treatment, and undignified deaths. They talked about humiliation on a collective level. Their stories evoked situations of manifest neglect and institutional abuse, referring, for example, to the lack of bodily care, lack of hygiene, loss of clothing, errors with medication, confinement in rooms measuring four square metres, arbitrary restraint measures (people tied to their beds for days), and forced transfers from one centre to another. This is how Noemí expressed it: "It's not just what happened, it's how they did it, it's the lack of humanity, the lack of dignity, it's so many things... There is so much pain in families."

The lack of adequate medical care and the decision not to refer residents to hospitals was especially outrageous. This was understood as a denial of a basic right and manifest discrimination. Some platforms referred to documents issued by the health authorities (Department of Health of the Generalitat of Catalonia) that talked about "limiting therapeutic effort" and "screening based on the age and value of the patient".

Until the second week of April, older people did not set foot in a hospital and died in care homes, in absolutely undignified situations. There are no words. Improper of a civilised state that uses the rule of law, and any sign of humanity. They died like dogs, worse than dogs. (María José, 5\*1 Coordinator).

Azahara's father died of cancer after being transferred to a hospital. According to her, befo-

re being transferred, a technician from the care home's Residential Care Team (EAR) admitted to her that they had decided to let his father die in the care home. After finally being transferred, her father became infected with Covid and, despite not having a negative PCR test, he was sent back to the care home. Through a personal contact, she managed to have her father referred to a nursing home, where he died thirteen days later. During the transfer from the hospital, Azahara saw him for the last time. Azahara confronted the doctor in the following terms:

'You can't discharge my father! By taking my father to the care home you are going to condemn him to die suffering and you are going to condemn him to die alone!'. The doctor told me that it is what it is, that my father was 82 years old, that he was occupying a Covid bed that another younger person with a better chance of survival could occupy. (Azahara, daughter, Marea Residencias).

In a similar way, Angel regretted that her 95-year-old mother had died from Covid in a hospital after being referred late by the care home. He also complained that in the hospital, she did not have access to a respirator:

My mother was the age she was, and they put her directly on morphine, waiting for her to die. There are documents where the Ministry of Health recommends that the few devices that were available go to another profile of people. It may make sense, but who decides about life and death? That is a fundamental human right. (Angel, son, Platform Affected by Coronavirus).

The pandemic measures (confinement, mobility restriction, isolation...) had serious health consequences for residents. Relatives confirmed the physical and cognitive deterioration residents suffered. They talked about people who "used to walk and no longer walk, who used to speak and no longer speak". Noemí found her father with much more advanced dementia and great loss of mobility. Clara's father did not recognise her and her sisters: "I have lost my father", she lamented.

Relatives' health was also affected. Many of them had to resort to psychological and pharmacological treatment. This is the case, for example,



of Soledad, who decided to remove her mother from the care home temporarily but had to return her because she could no longer provide care at home and could not afford to hire a care service. She has been receiving psychological help since then to handle her guilt and pain. In a similar sense, Noemí said, "I have been on medication since I took my father to the care home. I don't want my father to be there, but he has to be".

### The political work of emotions

In this context, some relatives organised themselves through associations and platforms to report the situation. Some of the most important are Marea de Residencias in Madrid, Coordinadora de Residencias 5+1 in Catalonia and Babestu and Pentsionistak Martxan in the Basque Country. Some platforms already existed before the pandemic, having emerged a decade ago to denounce the effects of funding cuts and austerity policies on care homes, as well as the privatisation of management by large investment groups (Bofill-Poch 2021). The pandemic amplified demands, bringing a greater number of families to a stronger and more articulated citizen response. The majority of participants were care-providing daughters, aged 55-69, from lower- and middle-class backgrounds, outraged by the events and determined to obtain moral reparation for what they and their relatives were suffering. They were informal care workers who took relatives to a care home when caring at home was no longer possible but who actively took care of them even they were in the care home.

It is difficult to determine the exact number of people involved in the organisations (which range from small associations to bigger ones with hundreds of members). In any case, the convergence between them is strong. In May 2021, the Plataforma Estatal de Familiares de Usuaris de Residencias (The Platform) was created. The Platform is made up of 19 associations from 11 Au-

tonomous Communities and has the aim of "uniting efforts throughout the country, demanding a new residential care home model, and acting as a single voice before the authorities". In the first major protest in the streets of the country's main cities, they called for urgent changes "for the thousands who died in undignified conditions". In Madrid alone, 1,500 people demonstrated. They denounced the commodification of the care home model, which entails precariousness and a loss of rights for older people and people with disabilities. They demanded a commitment from public authorities to the implementation of a Residential Care Homes Act.<sup>7</sup>

They also filed lawsuits against government agencies and care home managers, both through administrative and judicial channels. They alleged violation of fundamental rights, ageism, and malpractice. The crimes charged were denial of assistance, reckless homicide, and the crime of degrading treatment. They also asked for "reparation for pain and the right to the truth". They argued that the coronavirus had brought to light deficiencies in the long-term care system that have perdured over time. Thus, the pandemic exacerbated discontent and catalysed it publicly, acting as a *moral breakdown* (Zigon 2007) or *critical event* (Araújo 2007).

Relatives use platforms to mobilise their grief in the public sphere. Self-identified as victims of care homes crisis, they organise public events and mobilisations, and use the media to socialise their pain and anger. In doing so, they politicised grief, and thus made it a collective, shared, politically induced grief. Politicising grief also meant politicising the deaths, so that they could be interpreted as the result of a social and political conflict (Pita 2010; De Miguel 2003). In this context, the deaths become an expression of the undignified and discriminatory treatment of older people during the pandemic, of the failure of health policies imposed at the expense of a care home model that requires a profound and urgent reconside-

<sup>7</sup> In June 2022, at the proposal of the Ministry of Social Rights and Agenda 2030, the agreement between the Government and the Autonomous Communities on the new care home model was approved, which sets a limit on the number of places, increases caregiver ratios and advocates the elimination of restraints. Relatives' platforms consider it to be totally insufficient. See <https://www.newtral.es/acuerdo-nuevo-modelo-residencias-ccaa/20220706>.

ration. On the basis of an emerging process of awareness-raising and political subjectivation, relatives transformed individual suffering—expressed in terms of guilt, pain, and anger—into collective action, on the basis of a shared sense of moral obligation, a duty of reparation and justice (Jaspers 2014). They thus transformed complaints about care home care into a demand for rights and dignity, into a political and citizenship issue.

In this process, guilt—felt by relatives who are no longer able to care for their loved one at home and have to delegate to the institution—emerged as an issue to be worked on collectively. As some platforms stated:

Guilt is inevitable. We always think, 'What could I have done to avoid this?' From Marea de Residencias we always try to say that it is not the relatives who are to blame. Relatives have not been able to do anything in this situation. People who are institutionalised are the responsibility of the institutions; they have to guarantee that these people are well cared for. We should never, at any time, blame external actors for this responsibility. (Carmen, Marea de Residencias).

Part of this process of political subjectivation involved placing value on the care provided by relatives, also within the institution. They questioned the health policies that led to the closure of the centres to visitors—abruptly interrupting the family care relationship and curtailing the autonomy of residents and relatives (Comas-d'Argemir, Legarreta-Iza and Garcia 2021). Relatives claimed to be an essential part of the care of residents. They asserted themselves as active agents in daily care, in decision-making, in communicating with the centre, in maintaining the resident's living space, in accompanying the resident, and in sustaining memory and social identity. As stated by Lola, sometimes they contributed to "many hours of dignity and care, making up for all these shortcomings that exist in care homes" (Lola, daughter, Estels silenciats).

The idea that relatives of residents "are something more than visitors" (Kemp 2021) appears

in the demands of the platforms, which claim the centrality of the care provided by relatives in sustaining the psychological and emotional well-being of residents and relatives themselves. According to sociological and gerontological studies on institutionalised long-term care (Stall et al 2020; Jackson and Gaugler 2016), relatives show the detrimental effects of not having considered such care essential, which means denying a vital dimension of care: the relational and emotional support provided by family. This affected not only the identity and well-being of the resident, but also of the family caregiver. It also meant denying the close interrelationship between formal care (provided by the institution) and informal care (provided by members of the resident's social network), revealing a narrow and biased conception of care as opposed to a holistic conception in which the different agents of care are understood as intertwined, constituting complex *mosaics of care* (Sorionellas et al 2022).<sup>8</sup>

Policies that conceived of family visits as non-essential were guided by a biomedical model of care that prioritised infection control over the relational dimension of care (Kemp 2021), something that had dramatic consequences in care homes. In the words of one geriatrician, these policies "triggered geriatric symptoms far more deadly than the virus itself".<sup>9</sup> According to Fassin (2021), it could be said that these policies reflect a *moral economy of life* that privileged biological aspects of life, and not so much social or biographical ones, without paying attention to the equally harmful effects of this prioritisation. In other words, health policies—especially during the first months of extreme restrictions—were aimed at preventing the spread of the virus, without addressing the specific needs of certain groups that suffered especially from the effects of lockdown. In the case of the older people in care homes, not only were they ignored and discriminated to a large extent against in their access to hospitals, but they also suffered the consequences of policies that

<sup>8</sup> The concept of *care mosaic* refers to the interweaving of care agents in the strategies that families mobilise to articulate the set of available family, state, market, and community resources (Sorionellas et al 2022).

<sup>9</sup> For a more detailed analysis of the effects of the lockdown on residents see Comas-d'Argemir, Legarreta and Garcia 2021. The quote from the geriatrician is taken from this report.



were insensitive to their needs and vulnerabilities. For some of them, lockdown was in a way even more lethal than the virus itself, also limiting at large fundamental rights, such as the right to be accompanied at the end of life.

### Final remarks

The pandemic had a huge impact on care homes in Spain, which can be explained on the basis of multiple factors, both circumstantial and structural. Residents, and also relatives, suffered the consequences of deficient care policies, but also of the neglect suffered by care homes during the pandemic. The protocols issued by the health agencies changed frequently and were misaligned with the needs of care homes, showing a lack of knowledge of the residential context. The health authorities were incompetent when they ordered or recommended actions in the care home setting. Supposedly protectionist measures aimed at older people living in care homes (the aforementioned lockdown protocols, mobility restriction, isolation, etc.) acted in practice as mechanisms of exclusion and marginalisation. Residents were not the main asset to be protected. Thus, under a security paradigm, some fundamental rights were suspended to supposedly protect citizens, but the real and unequal effects of these policies were never evaluated. Under this paradigm, initial inequalities were accentuated, and the specific needs of vulnerable groups were neglected. Alarmed by the high rates of infection and mortality, families were left to decide what to do with their relatives within the institutions. The guilt of not being able to deinstitutionalise their relatives, coupled with the anguish, uncertainty and pain of isolation and the loss of the ability to care for them, initially expressed in more individual terms, gradually turned into collective indignation, as a sense of collectivity or moral community took shape (Das 1997).

The *emotional grammars* that permeate and underpin relatives' protest and victimisation processes (Coelho and Pardo 2018; Coelho and Beleli 2022) offer different meanings. Guilt, pain, and anger are linked, sometimes in a slippery way,

On the one hand, the emotions embodied and expressed by these family members are motivated and have to be understood in the light of the cultural context and the specific conditions they have experienced as caregivers. Thus, guilt is related to family values and caregiving responsibilities. The anguish, grief, and anger felt at the way the pandemic was handled in care homes (especially difficult moments, such as death) are related to notions of deserved care, human dignity, and the treatment of older people and the body of a deceased person. These are socially shaped notions, linked to a time and a social context, to shared values and beliefs (Le Breton 2009).

On the other hand, these emotions also have a political charge: They drive the mobilisation of families who feel pain and anger, in an attempt to seek justice and demand accountability—more immediately, from the care home management and more broadly from the public authorities. Emotions became a clear driver for action for family members (family caregivers), which until now had remained silent and generally under-politicised (Durán 2018). The care home crisis produced a real moral breakdown (Zigon 2007) or moral shock (Jaspers 2014). Certain boundaries were crossed. Conflicts and grievances that before the pandemic were experienced in a muted way were now felt more intensely. The pandemic led to a greater awareness and prompted families to openly formulate demands that had previously been expressed in a more fragmented and inarticulate manner. This politicisation and protest in the public sphere took place at different levels, and not without some ambiguity, with some families claiming care as a fundamental right and a duty of society as a whole and others (or the same ones, to a certain degree) still carrying the guilt and burden of conceiving care as basically a family obligation.

The political value of such mobilisations lies precisely in their ability to place the responsibility for the provision of care on the public authorities, demanding its redistribution and socialisation beyond family care. Protest and the struggle

for the dignity of older persons emerged here as a moral device, criss-crossed by gender and kinship—a duty felt by sons and, especially, daughters—as a practice inseparable from the very duty to provide care. In their actions, relatives also claimed to be a central agent of care within the institution, expressing what on a political and academic level has been identified as a (desirable) transition towards a more holistic and flexible model of residential care, centred on the person and linked to the community: a resignification of the right to care and to be cared for.

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### Raúl Márquez Porras

Ph.D. in Social Anthropology from the University of Barcelona (UB), in Barcelona, Spain. Associate Professor in the Department of Social Anthropology at the University of Barcelona, in Barcelona, Spain.

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### Sílvia Bofill-Poch

Ph.D. in Social Anthropology from the University of Barcelona, in Barcelona, Spain. Associate Professor in the Department of Social Anthropology at the University of Barcelona.

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