

Care Homes in Spain in the COVID-19 Pandemic: Lessons Learned from an Intervention by Médecins Sans Frontières

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Abstract

When the COVID-19 pandemic struck in early 2020, it rapidly became apparent that older individuals were at greater risk of serious illness and death. The risk was even greater for residents in care homes, who live in close proximity and may be suffering other comorbidities. Such facilities also saw a high turnover of staff and visitors, meaning an increased risk of transmission. Data has suggested that care home residents may account for up to a half of all COVID-related deaths in Spain.

As morbidity and mortality for COVID-19 was increasing in March 2020, MSF offered support to Spanish care homes during the first wave of infections. Our intervention included different axes: advocacy, knowledge sharing, training and implementation of measures for a reduction in transmission and for infection prevention and control (IPC).

The situation for care home residents was dire, with many people dying alone, away from loved ones and without access to palliative care. Staff were overwhelmed and ill-equipped to deal with the scale and complexity of this tragedy.

Although technical interventions to reduce transmission were crucial, it became clear that other people-centred activities that supported residents, their families and staff, were of equal importance, including facilitating contact between families, providing emotional support and offering adequate pain management and palliative care.

Residents in care homes have the same rights as everyone else. In the event of future crises, the most vulnerable should not be neglected.

Keywords: COVID-19; care homes; MSF; Spain

Introduction

The disease caused by a hitherto unknown coronavirus, and denoted coronavirus disease 2019 (COVID-19) was designated a pandemic on 11 March 2020 (World Health Organization, 2020a). The first case of COVID-19 was detected in Spain on 31 January 2020, and as of August 2021 there have been more than 4,500,000 cases and over 80,000 COVID-19 deaths in the country.

Given the novelty of the virus, there was a lack of basic information about the pathogenic mechanisms, transmission and why some people are more affected than others, and this hindered the initial response to contain the outbreak. This meant that regional and central governments in Spain, politicians and social organisations did not take the threat seriously enough at first (Baron and Rahmouni, 2020).

International organisations, such as the World Health Organization (WHO) and Médecins Sans Frontières (MSF) – a medical-humanitarian organisation with extensive experience in situations of human distress such as armed conflicts, epidemics and natural disasters in lower income countries – were completely unprepared to face a crisis of this magnitude.

From the outset of the COVID-19 pandemic, one of the few certainties was that the risk of serious disease increased with age and comorbidities, therefore older residents in care homes would be particularly vulnerable. In these centres, many residents live together in closed spaces with a high turnover of people entering and exiting these facilities; these conditions are particularly conducive to propagation of infection (European Centre for Disease Prevention and Control, 2020). The risks to those living in care homes is reflected in the alarming statistics. During the first weeks of the pandemic in Spain, more than 6 per cent of the overall care home population (333,920) died due to COVID-19 or with symptoms consistent with the disease (Comas-Herrera *et al.*, 2020). A report published in November 2020 by the COVID-19 and Care Homes Working Group suggested that deaths in care homes may have contributed to approximately 50 per cent of all deaths (Ministerio de Derechos Sociales y Agenda 2030, 2020).

As MSF was involved at the beginning of the response when fatalities were high, we witnessed first-hand the suffering of the care home residents, families and staff – something that was unthinkable in a European country with a robust healthcare system. In this article, we reflect on our experience and some of the lessons that can be learned for future epidemics.

Evolution of MSF Intervention

In March 2020, there was a steep increase in critical COVID-19 patients leading to a shortfall in hospital beds,

including beds in intensive care units and for those patients needing access to respiratory support. Supporting emergency response is where MSF has its added value, and after seeing the health system was on the verge of collapse, MSF directly collaborated with local authorities responding to COVID-19. Initial efforts focused on proposing and executing solutions for the decongestion of hospital emergency services, the supply of oxygen and the maintenance of referral systems in the two regions with the highest morbidity and mortality, Madrid and Barcelona.

Once the intervention had started, it soon became apparent that the most vulnerable group was the older population living in care homes. Infections and subsequent mortality were accelerating due to the high concentration of older individuals, with many dying in loneliness, unassisted, in inhumane situations. MSF refocused its activities prioritising this vulnerable population.

Almost one hundred MSF staff worked for two and a half months on this response. The staff were drawn from different backgrounds, including medical doctors and nurses, mental health professionals and logistics experts. Seven MSF teams directly supported 486 care homes from 19 March to 22 May 2020 in nine out of seventeen different Spanish regions.

On 19 March, as requested by the advisory board of one of the leading care home associations in Spain (representing private and government-sponsored structures), mobile teams were deployed to some of the most affected care homes in Catalonia. Our intervention then expanded to other regions of the country, but the level of collaboration with authorities and amount of access to care homes varied between different autonomous communities (*comunidades autónomas*). We do not have a clear understanding as to why we were granted access to some care homes and not others.

Two options were considered: to concentrate all efforts in a few care homes or try to reach as many centres as possible. Given the urgency and lack of data, MSF opted for the latter as there was not enough time to identify the most exposed and vulnerable individuals.

Despite the efforts to try to identify risk or protective factors within the care homes, it was impossible to determine a pattern. For example, facilities with more medical staff and more financial resources could be more affected than other care homes with fewer resources. A system was developed to identify those most at risk, but the initial analysis of the pandemic behaviour was completely random, regardless of care home size, resources or structure.

Pillars of Care Home Intervention

MSF provided onsite and virtual assistance, offering technical advice and training in different kinds of residential care homes. Our work was centred around three main pillars:

knowledge sharing and training, implementation of IPC measures in care homes and advocacy.

Knowledge sharing and training. The scientific evidence to guide such a complex response was not available at that point in time. MSF therefore created several MSF working groups composed of people with experience of working in epidemics focusing on areas such as (a) mental health and psychosocial support, (b) palliative care and (c) infection prevention and control. These working groups helped to guide the intervention from an emergency and humanitarian response perspective. MSF gave advice and spoke out on how to manage a complex context, with high mortality rates and directly affecting a vulnerable group of the general population.

A dedicated website was developed for the local authorities, health and care managers and professionals, with the aim of sharing knowledge, guidelines and best practice. A mobile phone application was also developed to facilitate easy access to information.

MSF organised webinars in which tools and technical guidelines with practical solutions to infection control questions and protocols as well as self-protection techniques were shared. By the end of July 2020, the website had received almost 76,000 visits and more than 9,500 people had participated in one of the thirty-eight webinars organised. The website was used in many countries in Latin America and remained open for a year with access to the published documentation and training.

Implementation of IPC measures in care homes. The teams who visited the care homes designed protocols for the segregation of residents. All structures differed from one another, each of them presenting different challenges to reduce transmission between people. MSF designed new ways of working that considered the movement of people and material through the facilities to reduce the spread of infection.

MSF developed user-friendly training materials, adapted to staff workload and different levels of education and expertise, conducted training on IPC measures and assisted with the design of contingency plans and evaluation of facilities. MSF also donated personal protective equipment (PPE), and when supplies were unavailable, supported care home staff to develop alternative solutions.

Advocacy. Throughout the intervention, MSF was lobbying the highest levels of authorities and wrote numerous letters, reports and briefing papers to raise the alarm about the situation in care homes and share our experiences (MSF and Amnesty International, 2020; MSF, 2020).¹ MSF had many meetings with parliamentarians, health and social care authorities, associations, the scientific community, private actors and collaborated with other civil society organisations such as Amnesty International and Médicos del Mundo

to put pressure on stakeholders to improve the situation in care homes.

People-Centred Approach

While working in the care homes MSF saw first-hand the tragedy and the ethical dilemmas the key workers were facing. Such dilemmas included whether to preserve hospital capacities for those who were most likely to survive (i.e. younger people) versus prioritising the needs of the most vulnerable (i.e. older people), or prioritising public health measures to reduce transmission (e.g. isolation) versus the mental health consequences of living or dying in solitude. MSF aimed to ensure dignified treatment and care while reinforcing individual autonomy. Support was given to care home staff to help residents with their mobility, as well as facilitating calls or face-to-face visits with their families. MSF also provided some assistance in the end-of-life process for the last farewell. This was all done without violating the safety protocols for preventing transmission.

The stress caused by dealing with the pandemic, particularly for those directly involved, such as care home staff, was immense. Left unchecked, this fear factor could rapidly lead to mental health consequences. MSF therefore aimed to provide support and counselling on this issue to residents, families and staff through a group psychologist.

MSF developed lines of work for emotional health support for the residents and staff. We also received and made numerous calls to family members to gather information and offer emotional support.

Closure of the Intervention

As the caseload and mortality rate declined, MSF informed the relevant authorities that it would be ending the direct support intervention on 22 May 2020. The decision was taken to enable MSF to redirect capacity to other, mostly, low-income countries where the organisation had operations that were becoming deeply affected by the pandemic. All resources were made available online so they could be used by others, a virtual assistant dealt with common queries and a phone line was set up in case of urgent requests for assistance until September 2020. The online materials were used by other countries, such as the Czech Republic, United States of America and Colombia where similar interventions were taking place. MSF also has ongoing advocacy activities to ensure care home residents are not forgotten.

Challenges Encountered

Initial Public Health Response Excluded Care Homes

In Spain, there is a decentralised system for health care that is the responsibility of each region. However, across

Spain, care homes lie outside of the health system and are considered social structures. The initial focus of the COVID-19 response was directed toward supporting the health system, therefore delaying the detection of residents and staff in care homes with COVID-19. They were left behind. Moreover, high rates of asymptomatic infection among staff and residents, together with a limited testing capacity, further hindered early recognition and implementation of appropriate IPC measures (WHO, 2020b). The lack of capacity to implement isolation, quarantine and physical distancing measures further increased infection rates.

Lack of Robust Data Systems to Identify Issues at Care Homes

Decision-making during the first wave of the pandemic was hindered by a lack of reliable data. It rapidly became apparent that the data-collection systems in care homes were (and continue to be) very fragile. Reliable statistics on the number of deaths, compounded by a lack of testing in care homes, were not available. Likewise, there were no reliable statistics for the number of patients in care homes, or crucial demographic data disaggregated by age, sex and health condition, to enable a detailed analysis of the impact of the pandemic on residents (Abellán García *et al.*, 2020). As the pandemic progressed there was also no data on the impact on care home residents – such as who died alone, who was confined without contact with loved ones and who received proper palliative care. Even today there is no accurate data on the number of people living in care homes, number and qualification of employees, availability of health professionals and services and so on. The COVID-19 pandemic exacerbated this precarious situation and the consequent impact on a particularly vulnerable section of the population (Abellán García *et al.*, 2020; *infoLibre*, 2021).

Inability to Refer Ill Patients to the Health System for Timely Care

Despite the principle of non-age-discrimination for medical care enshrined in Law 33/2011 on General Public Health, during the COVID-19 pandemic patients that were sick were often not being referred, or were referred too late, to the health system. Referrals or preferential circuits for transferring infected people to other centres or hospitals were not prioritised and, in some cases, not allowed (Rico, 2021). This was happening in most care homes that did and did not have medical staff on site. Denying a hospital referral without offering an adequate viable alternative could incur an omission of the duty of assistance, which several courts are currently investigating. To date, MSF has not been requested to testify in any of these cases, and

proactive legal actions were not discussed within the organisation.

Care Home Teams Ill-Equipped to Deal with COVID-19

As well as a lack of trained medical staff in many care homes, there was a widespread lack of staff trained in emergency response to epidemics and infection control. The long hours and stressful environment meant that workers had little time to read and absorb protocols and operating procedures as they became available. The emotional health of care home staff was seriously compromised and not taken sufficiently into account by health authorities, aggravated by a severe shortage of PPE. The general confusion as to the roles and responsibilities of staff led to high rates of absenteeism due to sick leave, further exacerbating the dire healthcare situation.

Staff and caregivers felt abandoned, not only in their caring role, but because they were faced with very challenging life-or-death situations daily. Without oxygen, a critically ill COVID-19 patient generally fails to survive, and the staff were left without proper support to deal with these complex situations.

Knowing that many of the residents in better conditions had been transferred to a medical facility, me and the nurse, decided to go and visit those who had remained in the residence that had just been vacated. The situation was desperate – approximately 30 residents in serious condition with respiratory failure, agitation and severe dehydration. A few staff were taking care of the last transfers of patients to the hospital and the management of dead bodies. And we humbly begin to do our work. First is to sort out who is who, where is everyone, which are the ones that need to be attended to most urgently, which are the ones that have died? We contacted the authorities so that these patients could be transferred immediately to more specialised centres. Some of them died waiting, others were referred – it seemed so unfair.

Coordinator, MSF care home intervention, Catalonia

Poor Coordination between Different Actors

The first months of the pandemic also exposed important structural issues. The decentralised nature of governance in Spain led to poor coordination and cohesion between central government and autonomous communities and resulted in late and unclear decision-making processes. Likewise, there was a lack of coordination between care homes and epidemiological surveillance systems (the test and trace programmes were initially absent or very limited), as well as between primary and specialist health care and between care homes and the healthcare system. More broadly the fragmentation of the care-homes set-up, combined with years of neglect, privatisation and

underinvestment in social services, helps explain the situation MSF found in the first months of the pandemic. This dysfunctional system led to care home residents ‘falling through the cracks’.

Rights of Older People Forgotten

In long-term care facilities, residents struggled with not being able to socialise with fellow residents or receive visits from their family and friends. Families were also extremely distressed that they were not able to visit their loved ones (WHO, 2020b). Simple solutions such as facilitating video calls between family members were often not being implemented; MSF raised awareness among staff in this regard, but their resources were very limited. MSF supported the staff in doing video calls:

The intervention became humanised at an incredible speed: it has a face, eyes, fear, and disorder. Many of the resident clung to our hands as if they were those of the person on the other side of the phone screen. Others say they are fine, that it is the staff who are tired and some, incredibly, manage to hold a conversation. Without exception, there is a change in the person that fills the environment with something like light – whatever it is, it looks like light.

Coordinator, MSF care home intervention, Catalonia

For people that needed palliative or end-of-life care, their care was often deficient, partially due to the absence of protocols to help guide these situations. The responsibility fell on care home staff who were not medically trained and did not have the knowledge or expertise to manage such sensitive situations, causing them hopelessness and despair.

Recommendations for Future Emergencies in Wealthy States

Interventions Targeting Care Homes Need a People-Centred Humanitarian Approach

Epidemics are social crises, not just medical ones. People with long-term care needs are often vulnerable and benefit from living together. They may require continuous, complex and personalised care and support to these structures is key during an epidemic. Assistive care for personal tasks requires high levels of physical and emotional contact. Access and good communication with primary health care, hospitals and palliative care access is essential to enable continuity of care. The COVID-19 pandemic distanced and isolated people, aggravating the already present uncertainties. The pressing technical needs and issues in the first wave (such as the need for PPE) clouded the fact that people were dying alone, without contact with loved ones and without access to palliative care. The response may have

lost sight of the most important element: the human factor.

While MSF focused on supporting the staff involved in the people-centred approach previously described, the organisation should still reflect on whether interventions got overly technical and should have placed more emphasis on dignity, facilitation of family visits and provision of palliative care from the outset.

Older People Must Be Treated with Dignity and Their Rights Must Be Respected

Many people, particularly older adults with long-term care needs, had been isolated in homes or facilities for many weeks, leading to reduced social contact and disrupted routines. Some people with long-term care needs, such as people living with dementia, experience decline in physical and cognitive status. Rapid changes to their routine may also have increased their vulnerability to pre-existing conditions (WHO, 2020c). The lack of contact with family members left people feeling very alone. It was also tragic that many people that should have been referred to the health system for care, ended up dying alone and in fear, often without basic assistance. Some of these deaths could have been prevented if a referral system were in place, and this is something that must be guaranteed for older people in future epidemics.

From March to April 2020 hundreds of residents were denied access to emergency services and hospital admission, their access restricted depending on the autonomous community and stage of the epidemic. With no alternative, care homes were forced to try and manage severely ill COVID-19-positive patients in their facilities. At the beginning of the epidemic this seemed to be due to the lack of prioritisation of the most vulnerable and to hospital overcrowding, but it is difficult to understand why alternatives were not put in place later to provide quality and humanised palliative care.

The requirement to guarantee and respect the rights of older individuals is enshrined in the main human rights declarations ratified by Spain (United Nations Human Rights, 1976a, 1976b). According to a 2003 recommendation of the European Council, palliative care is a vital and integral part of any health service. Although MSF has only recently started to gain expertise in palliative care, a lack of protocols dedicated to comfort, sedation and palliation for terminally ill people who had not been referred to hospitals or other facilities was observed at the time. In Spain, not all communities have regulated the right to palliative care and a dignified death: only nine of the seventeen autonomous communities have done so. One of the main challenges MSF faced was working in facilities where this essential service was not integrated in the service provision (*Derecho a Morir Dignamente*, 2020).

Anyone who needs palliative care should have prompt access in all settings: the objective is to achieve and maintain as high a quality of life as possible for patients, attending to physical, psychological and spiritual needs associated with advanced disease through a multidisciplinary and sufficiently resourced team. On a practical note, legal documentation and last wishes should be available to those who are receiving palliative care. We emphasise the importance of equitable access to health and palliative care for older adults and people with existing conditions during the COVID-19 pandemic, regardless of their place of residence.

Another challenge was to solve ethical dilemmas emerging during the most severe phase of the pandemic, such as respecting decision-making in residents and ensuring rights to life and palliative care. These issues could have been addressed if dedicated platforms such as ethical committees, such as those that exist in the health system, had been available.

Public Health Responses Must Be Strengthened to Consider Care Home Residents from the Outset

Data collection systems and coordination between other actors must be improved. Without reliable information, we cannot fully understand what happened in care homes.

MSF encountered many issues related to the lack of coordination between actors involved in the COVID-19 response, but this is not the focus of this article. However, it is clear, that basic information was unavailable for an effective coordinated emergency response or to elaborate evidence-based public health policies. Data systems with adequate demographic information about residents must be linked to broader epidemiological surveillance systems to quickly identify and respond to future outbreaks. Also, given the vulnerability of care home residents, these structures should be prioritised for the allocation of human and financial resources, as well as key commodities for IPC, such as PPE. Standard policies and guidelines for effective detection, surveillance and control of outbreaks, that respect the dignity and emotional well-being of residents, their families and staff, must be available so they can be quickly implemented.

Adequate Human Resources with Some Capacity to Respond to Emergencies Must Be Included in Care Homes

During this epidemic it has become clear that in order to offer health care and not just social care in care homes there must be adequate human resources both in terms of numbers (ratios of staff to residents) and qualifications and training. Proactive and innovative recruitment and training mechanisms should be implemented to increase qualified staff numbers (e.g. recruiting retired staff, students from health and long-term care training

programmes) and these should be accompanied by rapid training programmes on IPC measures. Given the lack of staff, task shifting of certain duties is a way to increase care capacity. Care home staff should be financially incentivised to encourage retention and compensate them for additional workload and stress. Also, the numbers of staff that work across multiple care home locations should be reduced, as this increases virus transmission between different care home sites. Facilitating transport and accommodation of staff should be considered to minimise the risk of infection during local outbreaks. Considering the sustained pressure to provide care to vulnerable groups in a pandemic situation, it would be particularly important to implement strategies to provide mental health and psychosocial support to staff delivering long-term care covering specifically training in palliative care.

Conclusion

The first wave of the COVID-19 pandemic led to much misery and suffering. Older people in care homes were particularly hard hit with an unacceptably high mortality. MSF were first-hand witnesses to this situation and found a system that was unprepared and ill-equipped to reach the needs of care home residents.

Structural and technical issues aside, one of the weakest aspects of the COVID-19 response was not adequately people-centred. Public health measures neglected to consider the human impact that a deadly virus would have on people. Care home residents were not prioritised in the response, and many residents either died alone, terrified or witnessed their neighbours dying of asphyxiation and deprived of human touch and warmth, without access to qualified medical care.

A humanitarian approach that contemplates care provision based on needs and prioritises the most vulnerable and neglected – in this case, older people, especially those living in care homes – proved to be adequate to respond to the actual circumstances.

Alleviating human suffering and treating people with dignity is essential for their survival. The COVID-pandemic has demonstrated the need to ensure that the most at risk are not left behind.

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Note

1 All letters can be consulted.

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