




Who is essential in care? Reflections from the pandemic's backstage

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Abstract

Since the beginning of the pandemic spread of the Coronavirus, societies have been reminded that the impact of Covid-19 and public health measures of infection containment reflect known gradients of inequality. Measures focusing only the (acknowledged) frontstage of the pandemic and neglecting its (unacknowledged) backstage—understood as those framework conditions indispensable for societies to thrive—have worsened the impact of social determinants of health on the most vulnerable, as shown by the deleterious effects of prolonged social isolation of residents of nursing homes. To reflect this phenomenon ethically, a framework is proposed which is inspired by the feminist philosopher Margret Little. At its core stands the assumption that caring for people and moral ends allows us to identify what is morally salient. This epistemological stance allows a critical look at the alleged dilemmas invoked to enforce brute, long-lasting policies of closing nursing homes in many places—especially in the light of their dubious effectiveness in preventing viral spread and the severe physical and psychological consequences for those affected. If moral salience is only fully perceived through the closeness of the caring relationship, the human suffering resulting from these policies reveals the utter inadequacy of the dilemma rhetoric used to justify them. This insight is illustrated by the personal experience of the author: He describes his role as an essential care partner of his mother living in a nursing home and forced into the role of a “visitor” who witnessed a constant deterioration of care. Based on an epistemological understanding of caring for making reliable moral judgments, potentially exclusionary effects of distinguishing essential from non-essential groups in care will be addressed together with the need to overcome strict boundaries between front- and backstage. Such efforts will strengthen the moral community of persons needing care, professional care givers and essential care partners.

Keywords

long-term conditions, care homes, case study methods, ethics of care/care ethics, ethics and dementia care

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Introduction and overview

In what follows, the author wants to reflect on the intertwining of “acknowledged” and “unacknowledged” roles both at the frontstage and backstage of the pandemic, as son of a mother living in a nursing home and suffering from mild dementia. Being a nurse, he acted as essential care partner for his mother together with his sister. Due to the pandemic spread of the Coronavirus, a prohibition of visits was pronounced. Knowing how quickly his mother would suffer from social isolation, increased delirium and fall risks, he demanded immediate access to her. After he was granted an exception under great pressure, he visited his mother almost daily and experienced a continuous decay in the quality of care for her and for many other residents. He repeatedly asked the management to allow regular, safe visits for essential care partners, which was repeatedly refused with reference to the “ethical dilemma between freedom and security.”

In trying to understand the ethical nature of this situation, the intertwining of roles (an experience not out of the ordinary in the context of a pandemic) and the experience of a massively increased vulnerability of the nursing home population, the moral epistemology of seeing, which is inspired by the work of the feminist philosopher Margret Little and her seminal study on the role of affect in making reliable moral judgments, is instrumental.¹ Reflecting on his own experience in his country on the base of this moral epistemology, three main insights will be formulated about how the felt dichotomy between front- and backstage of the pandemic can be overcome when health care professionals try to respond professionally, personally, and ethically to the pandemic’s challenges.

The front- and the backstage of the pandemic

After more than two years since the beginning of the pandemic spread of the novel Coronavirus, many societies are still sailing through the tides of the Covid-19 pandemic and trying to mitigate its repercussions on the welfare and health of individuals and communities. Since the beginning of the pandemic, they have been reminded that—despite the initial novelty of the pathogen—not only the impact of Covid-19 itself but also of public health measures of infection containment, carry unequal burdens for those concerned that follow well-known gradients of social inequality.^{2,3} In addition, mistrust in science, but also unthinking scientism, populisms, or parochialisms in determining who is most in need or who deserves to be prioritized in allocation of scarce resources, have shown the “syndemic” nature of this pandemic, that is, the synthesis of pre-existing epidemics with Covid-19 causing particular harm not only to known medically vulnerable populations but also to socially disadvantaged groups.⁴ In determining the impact of this pandemic on vulnerable populations, social determinants have been described to act not only individually but also to interact intersectionally,^{2,5} as is the case for children living in poor neighborhoods with limited access to testing facilities, single parents having to organize remote schooling, frail people living in nursing homes, people affected by mental illnesses needing continuous outpatient assistance, or undocumented persons seeking for access to vaccines. Now, at the latest, as many societies are cautiously preparing for the most sought-after “endemic phase” of viral spread controllability—and hopefully no dangerous virus variants will put a spoke in the wheel of “reopening” measures—the “pandemic forgetfulness” of the present generations seems to belong to the past⁶ and is mutating into a sort of everydayness of the virus’ presence, requiring well-established mechanisms of societal adaptation to epidemiological dynamics.

Different actors have shaped the public health response to the pandemic threat on societal functioning. This *frontstage* of the pandemic was publicly perceivable and received considerable media coverage. It also made visible the extraordinary commitment of many nurses and doctors—often to exhaustion and beyond—in preventing premature death, saving most lives under conditions of resource scarcity and alleviating physical and psychological suffering. Together with the work of many educators, scientists, health authorities, ethicists, and others, this commitment was soon reciprocated by societal recognition of the systemic relevance

of these professions for securing the welfare of the community. But behind this *frontstage* of the pandemic and the publicly acknowledged commitment of professional actors there has always been a *backstage* which showed the—often unacknowledged—social, economic, and health-related burden of public health measures on the lives of individuals, families, and communities, and uncovered additional patterns of vulnerability^{2,3}: Nurses leaving their young children home alone while schools were closed, teachers worrying about their parents in nursing homes, doctors whose parents required intensive care, domestic workers with precarious working conditions not affording personal protective equipment for public transportation, etc. It was precisely this coincidence of roles—as professional, parent, child, sibling, grandchild, or neighbor—and the overload for many individuals who had to fulfill these roles between front- and backstage, that made the pandemic *ubiquitous*, as the term pan-demic itself implies, affecting virtually everybody and in different roles, though not everybody was equally vulnerable.

Worldwide, crisis standards of care have been formulated to inform and direct public health responses to the pandemic threat, most of them focusing (usually urgent) “frontstage issues” of infection containment and securing the functioning of healthcare systems.⁷ As the dynamic of the pandemic has shown, the claim to assess validly its impact on people’s lives by neglecting “backstage issues” has proven to be highly deceptive, since this impact is considerably triggered by social determinants of health as driving forces of the backstage.³ But beyond mere neglect, there is evidence that when public health interventions, aimed at containing the impact of the pandemic, are ethically blind for the backstage—understood as the sum of those unacknowledged, but at the same time indispensable framework conditions that must be met for any society to thrive—they will inevitably exacerbate the impact of these determinants on those most vulnerable and eventually even thwart the success of measures at the frontstage.^{7,8}

A sad reminder of this fatal dynamic is the evidence about the deleterious effects of the prolonged (and in many facilities still ongoing) social isolation of vulnerable populations facing disorders of consciousness and other illnesses, frailty, or imminent death^{3,9,10} which has been based on a predominantly biological account of vulnerability.¹¹ At the heart of this account stood the conceptualization of Covid-19 not as a *syndemic*⁴, requiring tailored answers to different patterns of vulnerability, but basically as a *plague*, to be solely averted by the logic of lockdown and measures of physical distancing.¹² Although these measures were initially comprehensible as long as the threat situation, the dynamics of viral transmission and the effectiveness of personal protection equipment were largely unknown, its medium and long-term consequences have been severe—both in nursing homes, hospitals and other healthcare facilities.^{13–15}

The moral epistemology of seeing

At the frontstage, the situation of nursing homes was presented as a *dilemma* requiring tragic choices which were enacted predominantly, but not exclusively, in the first waves of the pandemic in many countries. They led to a prolonged segregation of the nursing home population from essential care partners and families. In trying to better capture the ethical nature of this situation, the moral epistemology of seeing, which is inspired by the work of the feminist philosopher Margret Little¹, offers a normative understanding that departs from the fundamental role of affect in making moral judgments that are reliable, i.e., that mirror authentically what is ethically at stake. Following this epistemology, ethical knowing can never be confined to reason alone, but presupposes ethical seeing of what is on the backstage, existentially matters to people, affects their lives, stands at the heart of their relationships, and explains their felt moral obligations.

In this line of thinking, caring for people and for moral ideals entails a moral perception that elicits specific emotions. In contrast to received ethical theories that require *distance* and do not consider affect to be of any help for moral reasoning, Little contends that only *closeness* within the caring encounter can guarantee “...to pick up what is morally salient” (p. 124).¹ Seeing through the eyes of caring can therefore be considered an affective state that transcends mere perception. It acquires epistemological quality insofar as it helps to sort

ethical complexity and allows autonomous understanding of what is ethically at stake (p. 117).¹ A major cause of overlooking what is ethically at stake is the “compartmentalization of reason and affect” (p. 118)¹ with reason as necessary and sufficient condition for moral judgments. In contrast to this “bureaucratic model of morality” (p. 119)¹ Little contends that affect—not detached reasoning—is crucial for moral knowledge. What is morally salient is only perceived through the closeness of the caring relationship, not through detached reasoning. This epistemological stance allows for a critical look at the multitude of alleged dilemmas that have been invoked to enforce the brute, long-lasting policy of closing nursing homes in many places, regardless of the severe physical and psychological consequences for those affected.

The construction of biological vulnerability

Before starting with the author’s personal experience, a critical clarification is needed when talking about the front- and the backstage of the pandemic and relating it to the context of long-term care. As indicated above, at the root of many public health policies stood the construction of a massive biological vulnerability of nursing homes’ population to the virus, basically based on the conceptualization of the pandemic spread of the Coronavirus as a plague.^{12,13,15} This construction was informed by available data about the incidence and severe impact of Covid-19 in people living in nursing homes,^{13,15} which had been translated into the imperative of protection of life encompassing ample visiting restrictions and, in many places, not refraining from prolonged isolation of individuals from essential care partners. But as available data strongly suggest,^{13,15} not only the institutional implementation of such a *biological* vulnerability was ineffective in preventing high rates of nursing home deaths from Covid-19 but it also resulted in a fatal collapse both in quality of life and quality of care, and increased *social* vulnerability, which in turn negatively impacted biological vulnerability.^{9,10,13,14} In this line of thinking, already the idea of distinguishing a front- from a backstage of the pandemic turns out to be deceptive, as it may evoke a false dichotomy between the biological and the social, resp. the *mandatory* of saving “lives” (the frontstage) and the *optional* of saving “livelihoods” (the backstage) in public health responses.¹⁶ If this distinction is nevertheless maintained in the context of the further explanations, it is intended to differentiate between the “acknowledged” and the “unacknowledged,” and more specifically, between the level of perceived public discourse and the level of experienced personal concern, but by no means to establish a moral weighting between the two levels. On the contrary, from the perspective of theories of care, only *together* front- and backstage can form a stable foundation for social life, whereas the separation of one from the other is always associated with high opportunity costs,¹⁷ for example, by ignoring the vital importance of the family for the functioning of the state.¹⁸

The personal experience as an essential care partner during the pandemic

Following advice from the Government of Switzerland in spring 2020, many nursing homes began enacting extensive visiting restrictions and bans. As many other relatives having family members in nursing homes, my spontaneous reaction was a sense of relief, thinking that my mother was safe. Until then, I visited her every second day, her room had become the epicenter of our family life. As essential care partner and nurse,¹⁹ I had always been in intensive contact with the nursing team, trying to translate not only from Swiss German to Italian but also her concerns and preferences in the light of a mild, but progressive dementia. My mother and I developed our code, and I learned a new alphabet of feelings and emotions. The nursing team used to call me when my mother was in confusional states or anxiety. It usually did not take me long and she felt safe again, knowing that I or my sister would soon come over, which she forgot a short time after. All the greater was her joy when she saw one of us—every day anew, as if we had not met each other for months.

From essential care partner to visitor

It was a shock when I realized that visiting bans also applied for family members having the role of essential care partners.¹⁹ “It is for your own safety and the safety of your mother” was the mechanic response of the nursing home manager when I argued that essential care partners are not just visitors.²⁰ In the previous weeks, I had already been carrying a face mask in the nursing home, voluntarily and long before the nursing team began. From one day to another, the close relationship between my mother, my sister and me got “epidemiologized,” reduced to a health risk.²¹ At the same time, it became manifest that the nursing home was completely overburdened by the demands of infection control and daily nursing care, with many nurses themselves being under quarantine. After a total embargo of information concerning the number of nurses under quarantine and the residents infected under the pretext of data protection, I repeatedly asked whether they could provide the agreed care. I soon realized that the omission of basic nursing care, food, fluids, and social deprivation would be equally deadly as this novel virus. I contacted the guardianship authority. The lawyer advised me to insist that—in the case of a resident with dementia—the legal representative must always have access, since the person is not capable of representing herself. This argument did not seem to impress the nursing home manager, so that I had to come up with harder arguments. I told her by phone: “I will hold you personally and legally accountable if you do not fulfil each detail of the home contract we have signed – food, basic nursing care, physical activity, daylight, fresh air, safety and fall prevention. This is what we are paying you for.” I hung up. A short time later she called me back: “In your case, I will make an exception. You are a nurse, and you know the rules.” I felt deeply relieved and humiliated at once, experiencing a level of dependence and powerlessness I had never imagined before. After three days of the enactment of the visiting bans, my mother and many other residents on her floor contracted the Coronavirus from a nurse assistant. My mother was admitted to a Corona ward for elderly people. After four weeks, she was discharged to her nursing home again, in a desolate state, unkempt, malnourished, and dumb. I thought that—with the aid of her family physician and me supporting the nursing team—we could achieve that she soon recovers, with sufficient food, fluids, anti-deliriant medication, and social contact. But there was still this visiting ban. After protesting again, I was given an exception status, felt once more at the mercy of the manager, but reassured, nonetheless.

“Your time is up; you have to go”

I was allowed to visit my mother in her room for exactly half an hour per day. When I began to see her again in the nursing home, I had entered a world that was forbidden to me, a building transformed in a spooky place, with residents confined to their rooms, and highly distressed nurses, many of them with signs of exhaustion in their faces, but friendly and grateful for the helping hand I could give in looking after my mother. From that day on, with few exceptions, I was in the nursing home every evening after work, until my mother died in December 2021.

The first evening I visited my mother after hospital discharge, Leyla (name changed), the evening nurse, came exactly after half an hour, after I had handed my mother the second glass of tea. She was still delirious and completely dehydrated. “Mr. Monteverde, your time is up, you have to go” she said in a stern voice. “I will not go” I told her. What could be wrong with giving your own mother to drink, I thought. I felt helpless and said: “My mother looked at me when I was a small child, and now it’s my turn. I will for sure not leave until she has eaten and drunk enough, get the police for me or tell the home management for me, but now I will for sure not leave.” She was visibly upset and left the room. I feared that she would soon come with a guard and chase me out, or that I had completely screwed up with the permit and would not see my mother again. Leyla came back a short time later, looked at me deeply concerned, and apologized. I was completely stunned, having expected a completely different reaction. I visibly breathed a sigh of relief. I asked her: “How are your

parents?” I knew that they lived in a country far away and that she was very worried. When she looked into my eyes, answering “Fine, fortunately,” we found ourselves at eye level in our concern as a daughter and a son, meeting not as nurse and visitor, but as human beings sharing existential concerns for their parents.

“It is difficult for all of us”

“Why did you get the permission to visit your mother and not everybody?” I was asked by a worried wife of a resident one day at the entrance of the nursing home. She was waiting in vain to speak with the nursing home manager and to see her husband who suffered from serious mental illness already before the pandemic. I replied: “My mother is not doing so well,” but I felt bad about it, and I knew that this reason must have seemed flimsy to her. The same evening, I wrote to the nursing home manager and to the company management and demanded the visit ban to be lifted immediately and safe corridors of encounter to be established for essential care partners. I repeated this request nearly every week and forwarded it regularly to the local health authorities. I also sent recently published research evidence describing the catastrophic effect of prolonged confinement of the most vulnerable, the unproven efficacy of visiting bans, and expert opinions about the access for legal representatives in nursing homes. If I got an answer at all, it was always the same: “Unfortunately, we have these rules that we must follow. It is difficult for all of us.” At the same time, rules in the public sphere became more relaxed, people were allowed to meet outdoors, enjoyed the spring, and planned the summer holidays abroad. On a Sunday walk in my village in late spring 2020, I saw a group of nurses sitting in the garden of the nursing home by the sun, drinking coffee, smoking, and bantering. A cheerful, lively sight—if there had not been the large nursing home in the background, all in the shade behind large fir trees, where in every single room the light was on despite broad daylight. I shivered at the thought of a possible explanation: that residents were not allowed to leave their rooms. And I wondered what these people behind the walls would feel and think. This logic of confinement and segregation continued for a long time.

Contrary to all expectations, my mother recovered very well from Covid-19, even though, as I was repeatedly told, she had all the risk factors that indicated a bad outcome. Her primary care physician, who was in close contact with the manager, said dryly: “Your mother has an astonishing toughness. You can be lucky she survived Covid-19.” For the nurses on the ward, having seen many who had not survived Covid-19, or have suffered from social deprivation and physical deterioration due to the separation from essential care partners, this had clearly to do with my daily presence. As summer approached, I took short evening walks with my mother almost every day. I used to wait until the evening, so that no-one could see us. During the very first walk, we passed a large rosebush, and she said: “The roses have already faded, I have completely missed their bloom.” I knew that she would attribute this to her forgetfulness (we overtly spoke about dementia), but I also knew the real reason, but was ashamed to tell her so.

“You may shower your mother”

In the second lockdown, I observed my mother scratching herself frequently until she became bloody. I therefore cut her fingernails weekly, but with little success. Soon I noticed layers of skin cream piling up on her legs. I asked Inaya (name changed), the evening nurse: “How often do you shower my mother?” She answered me in an irritated tone, “As usual, once a week.” But I became skeptical. In my helplessness, I took pictures of shampoo and soap, which were placed in the shower stall. After a week, they were still in the same position and had a layer of dust. I asked again: “Do you have time to shower my mother?” I felt bad about it but noticed her unease. At first, she said, “Yes, we’ll shower her according to the schedule.” I asked her to just tell me the truth, I knew they were busy but if they did not have time I would do it myself, as I used to do it when she was at home. Finally, she said, “It’s because of the aerosols.” “Excuse me?” I asked incredulously. “The aerosols? But surely the bathroom has strong ventilation, we’re both vaccinated, and I wear a FFP2

mask.” A welcome excuse, I thought. “From now on, I will shower my mother weekly,” I told her in a firm voice. “But I still have to clear that with the ward manager,” she replied quietly. “Yes, do that” I replied. The next evening there was a note on the pin board in my mother’s room, “Hello Mr. Monteverde, you may shower your mother. Thank you for your help, Inaya” and next to it a pile of fresh towels. This note became for me a symbol of surrender and honesty at the same time. It helped me understanding the great pressure the nursing staff was and the willingness not to hide this from my eyes. The note still hangs on my refrigerator door today.

An unreal scenario

Even under difficult conditions, we had a sort of family life, with regular videocalls with her sisters, brothers, and nephews in Italy and other friends. She enjoyed the pleasant things and felt safe when I or my sister were around. She also listened attentively to some ethics lectures I gave via Zoom in the evening about pandemic-related topics. Although she could not follow the details, she realized that the contents had something to do with her and with us. One evening, I was even able to conduct a very short interview with her in a videoconference with a close group of family doctors. The topic was “visiting policies in nursing homes.” The scene with me and my mother sitting next to each other seemed completely unreal to them. They told me about the resistance they encountered during visits to their patients in nursing homes and reflected to me the privilege I had of being able to see my mother daily.

Exiting the “Corona-mode”

As the Covid-19 waves continued and even rolled over, the shortage of nurses became increasingly apparent as well as the deterioration of the quality of care. It had become evident that the nursing home did not manage to exit the “Corona-mode.” There were frequent staff changes, many positions of registered nurses and ward nurses remained unfilled and the workload for the individual nurses, who were often only poorly qualified, increased enormously. Again and again, I asked the management how they could meet the standards of care for all residents, but also ensure that nurses, assistants, and other staff wear protective masks continuously and correctly. My mother’s condition was frail, dementia, and delirium states increased. My trust in the nursing team dwindled and I increasingly felt myself becoming the prototype of a “troublesome relative.”

Although fall prevention measures were firmly planned following regular assessment, I noticed in my daily visits that they were implemented only very patchily in the course of the Corona-waves. Again and again, I approached the nurses about this. After a preventable fall, my mother died in the hospice, in the wake of surgery and several days’ stay in an intermediate care unit. To me, these events were clearly attributable to the “Corona-mode” the nursing home was still in. The fall protocol, which the nursing home manager sent me days later only upon my explicit request, asserted that my mother had “intentionally pushed the contact mat to her side so that she could get up unnoticed.” Never in the last four years have I noticed such sophisticated behavior, which would have alerted me immediately. Other preventive measures, although fixed in the care plan, were not in place. I found it outrageous that the nursing home wanted to blame my mother for the fall with a blatant lie. After sending a request through an attorney for clarification and my observations of the poor quality of care “since Corona,” the company manager himself answered with a detailed letter of regret and condolences for what happened. Even though I had already drawn attention to the problems in numerous letters before, I would like to assume his words were serious. My lawyer told me I had enough evidence to file charges. It is only the example of my mother, but also the moral courage and honesty of the nurses Leyla and Inaya, that prevented me from doing so.

Between restraining oneself and being courageous

During these experiences on the backstage of the pandemic, I actively participated in many discourses on the frontstage: triage criteria for scarce ventilators, prioritization of vaccines for health care professionals, vaccination strategies and prioritizations, distance learning with students working on Covid-19 wards, and the moral distress of healthcare professionals exposed to health risks, delivering unsafe care, or fighting against physical or/and moral exhaustion. In these contexts, the distinction between the “professional” and the “personal” was not always easy, for example, when discussing about compulsory vaccination of healthcare professionals or about a tougher enforcement of visitation bans in intensive care units, because managing “too many exceptions” was considered too time-consuming for some nurses. I had to learn to exercise restraint, always thinking of my “fellow relatives” in the nursing home my mother lived and wondering why family members could be considered as disruptive factors, and not as essential for the patient’s wellbeing. I found that their voices, jointly with the voices of residents, patients, essential care partners, and families, were painfully missing when it came to discuss visiting policies or the process of working through this public health crisis, which, with respect to the situation in nursing homes, the Canadian philosopher Monique Lanoix justifiably referred to as a humanitarian crisis.²² A particular challenge were the occasional video talks with some colleagues who were sun-tanned, well-fed, relaxed, and in a lovely place in the home office, with united family and in a safe place with plenty of space. They wanted to know what was going on at the “Corona front” and how bad the triage was at the hospital. That people in nursing homes needed special protection through social distancing measures was not a question for them, it was just a dilemma to get through. It was at this moment that I discovered Margret Little’s discourse about the role of affect in moral epistemology,¹ and relatedly, the ethical relevance of seeing. It gave me both clarity and the necessary insight that not everybody could “see” the same, since not everybody was equally affected.

Conclusions at a normative, personal, and political level

As initially stated, Little’s approach in moral epistemology¹ was chosen to better capture the ethical nature of the situation of “closed doors” many residents, essential care partners, families, and healthcare professionals were confronted with. In reflecting these policies and practices together with the intertwining of front- and backstage during the pandemic, the author identifies three possible conclusions:

At a normative level, a first conclusion relates to the way human suffering generated through prolonged segregation has been classified. There has been a lot of talk about “ethical dilemmas” surrounding nursing homes under the pandemic. Having in mind the “backstage” of many nursing homes and their metamorphosis into “total institutions,”²³ the evidence about the immense suffering and deaths through prolonged segregation and physical disruption of core relationships,^{9,10,12,13,15} but also the scant evidence of these drastic measures in preventing viral spread in nursing homes,²⁴ the term “ethical dilemma” appears both belittling and hurting. As aforementioned, in contrast a “bureaucratic model of morality” (p. 119)¹ Little contends that affect—not detached reasoning—is crucial for moral knowledge. What is morally salient is only perceived through the closeness of the caring relationship, not through detached reasoning. This epistemological stance allows for a critical look at the multitude of alleged dilemmas that have been invoked to enforce the brute, long-lasting policy of closing nursing homes in many places, regardless of the severe physical and psychological consequences for those affected. Departing from a moral epistemology of seeing what these policies could lead to in term of harm, and the unproven effectiveness in preventing viral spread, not moral dilemma, but the term moral aberration seems more appropriate here.

Of course, also in the author’s country, there were many good examples of nursing homes that overtly faced moral dilemmas in the best possible way and negotiated viable, humane solutions by providing safe corridors of encounter. These managers and nurses must be applauded for the way they tried to understand and

solve the excruciating dilemmas this pandemic posed and still poses. But in the many cases of moral aberration in failing to protect the most biologically and socially vulnerable—tragically symbolized by barbed wires around nursing homes, security guards armed with batons and barricaded windows—expressions of moral regret and moral apology would be needed to reestablish moral trust and realize again what the core mission and justification of these institutions is.²⁵ In Switzerland, the author has heard little about it so far. A reliable basis for this dialogue could be the comprehensive scientific report commissioned by the Federal Office of Public Health evaluating the management of the pandemic in Switzerland until summer 2021.²⁶ Among others, the report states that “... the interests of people living in institutions were not sufficiently taken into account at the beginning of the pandemic. Where binding regulations were made by the cantons, this was often done too sweepingly and without taking into account the negative side effects. In addition, the prohibitions on visiting and going out did not prevent the strong spread of Covid-19 in the institutions, as a high proportion of the staff also became infected and presumably contributed to the spread of the virus.” (p. 96s)²⁶

If this dialogue is to succeed for the future, it will require a united, inclusive effort of all involved stakeholders including ethicists, to shape public health policies and crisis standards of care that respond effectively to the biological *and* social vulnerability, acknowledge ethical dilemmas by reconciling the demands of safety and the maximization of liberty and choice,²⁷ but also name and sanction unjustified restrictions of personal freedoms.

A second, personal conclusion relates to question of who is essential in care. Since the first response to the pandemic by the courageous, energy-consuming, and highly professional commitment of countless nurses and doctors, the discourse on essentiality in care has served to mark both the irreplaceability, social value, and gratitude of the public for the dedication of health care workers who are honoring their profession in a unique way. At the same time, there were surprisingly few echoes from health care professionals and organizations claiming the irreplaceability of essential care partners in assuring both quality of life and quality of care. There were even voices arguing that an “excessive” presence of families could be too intrusive or disturbing for working safely on the ward.²⁸

When creating distinctions between who is essential in care and who, as an implicit consequence, becomes dispensable, the discourse about essentiality can become exclusionary and increase social vulnerability. After more than two years of pandemic, a moral epistemology of seeing requires that the forgetfulness of the family can be overcome and its vital relevance for good, safe, and person-oriented care reconfirmed, restoring the family system as a vitally important and reliable care partner.²⁹

A last, political conclusion relates to a politics of inclusion of both those who give care—as caregivers and essential care partners—and those who receive care, in shaping policies that effectively respond to the biological and social vulnerability within public health crises. In line with Tronto, this politics can be considered a genuine expression of democratic caring,³⁰ addressing not only individual vulnerabilities but also structural injustices that have made up the syndemic nature of this pandemic, triggered by the marketization of the long-term sector.³¹

In translating insights from a moral epistemology of seeing and the seminal role of affect in making reliable moral judgments, these conclusions can help to come to terms with what happened in many places within the long-term sector and foster reconciliation. They can also give orientation for all stakeholders towards future policies which meaningfully integrate the experiences of the acknowledged and unacknowledged protagonists of this pandemic. Further, they can raise the awareness for the importance of protecting the most vulnerable, maximizing choice,²⁷ and being responsive both to the biological and social dimension of vulnerability. Finally, they can address and mitigate concomitant human suffering, and forge the moral community of persons needing care, professional care givers, and essential care partners.

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