

## editorial

# Care goes viral: care theory and research confront the global COVID-19 pandemic

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## The hidden truths about caring revealed by the COVID-19 pandemic

As the COVID-19 novel coronavirus spread in late 2019, it quickly transformed from a local outbreak to a regional and then an international epidemic. Within three months, it became the global pandemic that many observers believe will irrevocably change the world and how we live in it. Among the most affected aspects of life will be how we organise and practise care and caring.

Plagues and pandemics have long shaped human history (Curson, 2006), as we have now been reminded. Despite the many advances of modern medicine, the destructive patterns of disease and disruption that are evident throughout human history did not end in the past; indeed, over the past century, these have continued in many different outbreaks, with vast human consequences (Hunter, 2007). There was, for example, no vaccine with which to end either the so-called Spanish Flu of 1918–19 which caused 40–50 million deaths, or the HIV/AIDS pandemic, which first appeared in 1981 and has so far led to 25–35 million deaths and immeasurable human misery. Alongside these major pandemics were others more specific in their impact: polio, Asian flu (1957–58) and Hong Kong flu (1968–70). While, to date, the number of deaths from COVID-19 remains lower than those from HIV/AIDS and many other diseases, the social, political and economic impact of the current pandemic is, and seems likely to be, far greater. Over just six months, use of the word ‘unprecedented’ (in English) to describe the transformations arising from the contagion, and from attempts by governments to manage and contain its effects, has rapidly become a cliché.

The perception of unprecedented social impact is heightened by the rapidity with which COVID-19 spread around the globe at a time in which social, economic and political conditions appeared to be ever more precarious. As it shifted from a virus carried by the relatively wealthy between countries, it also became more socially dispersed, impacting especially harshly on disadvantaged, socially marginalised and

exploited population groups. Governments had long been warned by epidemiologists, virologists and others to plan for such biosecurity hazards in the 21st century. Popular films, such as *Contagion*, *Outbreak* and *12 Monkeys*, rested upon, and gave visibility to, the real work of such scientists. However, in many countries, public preparations had not kept pace – or, worse, had been deliberately cut.<sup>1</sup> As a result, the impact of the virus has exposed many weaknesses and vulnerabilities in modern societies, providing a unique opportunity to more directly observe and understand their typically hidden inner workings.

In all of this, we argue, care has ‘come out’, emerging from the shadows as a taken-for-granted afterthought in public life. Through spontaneous (and nearly spontaneous) events around the world, healthcare workers were rapidly cheered as heroes. Yet, once people began to see the scope of ‘essential services’, less visible care workers who are often ignored or forgotten, alongside supermarket shelf-stackers, became ‘essential’. Soon, ‘essential’ came to include cleaners, transport workers and delivery drivers, as well as childcare and eldercare providers.

At all levels – from the macro concerns of public healthcare, acute hospital services and specialist medical care, through social care services in residential, home and community settings, as well as childcare providers of many types, to the micro levels of unpaid ‘informal’ care in the domestic sphere – care can be seen as political. The strengths of successful responses to the pandemic and the failings of other strategies can all be traced back to how care, understood in this broad way, has been enabled, supported, managed and matched to needs.

The capacity of any society to provide all forms of basic care is expressed through myriad fundamental decisions about how to organise services and to block or support, regulate or deregulate, various forms of care. These decisions define political life in its fullest sense. As one example, consider whether a given society invests little or a great deal in public health. This is a political decision but a fateful one when faced with a spreading infectious disease.

In contrast, critical care theory, along with most contemporary research on care and caring, has its roots in the feminist, civil rights and liberation movements of the late 1960s and 1970s (Tronto, 1993, Fine, 2004). It first focused attention on the hidden work of (mostly) women enacting essential responsibilities for childcare and family and domestic support. Later, it was rapidly applied to the work of disability support and aged care as a more extensive sense of care as an ethical concern for the ‘web of connections’ binding people and the world around them also developed (Tronto, 1993). Critical care theory’s historic context was one of social change, in which improvements in population health came to be expected and infectious diseases were, it seemed, increasingly relegated to the past. It was part of the so-called ‘epidemiological transition’: the historic transition from societies with short life expectancies in which infectious diseases and epidemics were the main cause of death, to ones in which life expectancy had increased dramatically. The main cause of mortality and morbidity had become non-communicable conditions and the diseases of later adulthood, such as coronary heart disease, stroke, diabetes, arthritis and cancer (McMichael, 2001). In recent decades, the emergence of ‘delayed degenerative diseases’ such as Parkinson’s disease and different forms of dementia were identified as a further stage in this epidemiological transition (Olshansky and Ault, 1986).

COVID-19 reflects a re-emergence of epidemics of infectious diseases over the past few decades, which includes HIV/AIDS, Hepatitis B and C, tuberculosis, Severe

Acute Respiratory Syndrome (SARS), Ebola, Dengue fever, Zika, and malaria, as well as new, mutated, forms of influenza and other respiratory infections, such as the avian flu viruses (CDC, 2020a; 2020b). This return of contagion across the globe, affecting not just lower- or middle-income countries, serves as a rejoinder to public optimism – evident from the time of successful vaccination campaigns against polio in the 1950s and smallpox in ensuing decades – that ignored the biohazard warnings and wrongly came to regard mass infectious diseases as a thing of the past (McMichael, 2001).

There is an urgent need to learn from the global crisis that the COVID-19 global pandemic presents. Immediate, practical responses have been widely called for, but as researchers and teachers, policymakers, activists, practitioners, carers, and people receiving and depending upon care, we also have a responsibility to step back, assemble evidence and reflect, so that we can draw informed and critical conclusions. In this editorial, and the accompanying call for papers, we seek to open the dialogue on the impact of the COVID-19 pandemic on all aspects of care. We canvas a number of notable issues in the following but recognise that this is, and must necessarily remain, an incomplete inventory of topics, being based on the present brief reflection on what remains essentially uncharted, barely studied, territory.

## Death by numbers: the epidemiology of care

Driving public awareness of the spread and impact of COVID-19 have been the epidemiological tables reported in the media and made readily available through its ‘COVID-19 dashboard’ by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU, 2020), WorldoMeter (2020), the World Health Organization (WHO, 2020) and national, state and provincial health authorities. These measures quantify, tabulate and offer graphs and other visual representations of the cases officially recorded and monitored in each country. Some record infection, hospitalisation, intensive care unit (ICU) use and death rates for each country at state/provincial and/or municipal sub-jurisdiction levels. Commonly expressed in logarithmic as well as arithmetic tables to capture the rapidly increasing incidence of the disease, these enable not only governments and relevant authorities, but also researchers, the media and individuals to monitor the progress of the virus and its known, or officially recognised, impact on the populations concerned.

The patterns of caring required to respond to the COVID-19 pandemic are unlike any that advanced societies had become familiar with in recent generations. The need for care had been expanding, slowly but inexorably, from the mid-20th century, driven by extensive socio-economic change as well as epidemiological factors. The increased and intensified need for ongoing personal care is reflected in population ageing statistics and the rising prevalence of long-term impairments and disabilities. Demand for childcare grew massively during this period too, not only as a corollary of the widening recognition of women’s rights to paid employment and a life outside the home, but also as a consequence of their growing need to seek paid work as economic life grew globally more precarious. The greater demands made of unpaid carers and professional care services reflected rising expectations about medical capabilities and social interventions, as well as a growing awareness of the rights of those who need long-term care (Fine, 2007; Yeandle et al, 2017). Providing care under these conditions is demanding, requiring prolonged and often increasing commitments over many years, frequently achieved through the massive personal

sacrifice of unpaid and primarily female carers, most of whom are family members. Alongside this, formal care arrangements also developed rapidly through social policy initiatives and private care arrangements. In recent decades, market-based reforms to public systems in most advanced countries have emerged; these have not reduced costs, but led to significant growth in private expenditure, alongside continued public funding (Aulenbacher et al, 2018; Fine and Davidson, 2018).

With COVID-19 and other pandemics, the mathematics and type of care required are different, more urgent and explosive than in other contexts. For most other illnesses, including chronic conditions, paths of treatment and routines of care are clear. COVID-19 presents new and different challenges. Some arise from its almost symptomless transmission; others from the virulent forms of pulmonary and other disease responses still emerging, and for which standard treatments have not yet emerged. Numbers of new cases grow fast, especially in the early stages, as each infected person transmits the contagion to several others who, in turn, transmit it to their own contacts. This rapid multiplication of carriers/sufferers can quickly overwhelm households, neighbourhoods and even well-intentioned healthcare providers. Carers are also affected. When caring involves physical contact with or proximity to affected persons, it becomes highly dangerous, directly threatening – and all too often ending – the lives of those providing care, and drastically diminishing capacity to provide care at the level and of the quality required.

Under these ‘pressure cooker’ conditions, care had to change rapidly. Existing provisions often failed or could no longer operate as before the crisis. Increased responsibility for care was placed on those at home, raising expectations about the unpaid domestic work women could perform (Hamilton, 2020). These developments may lie behind reports of a sharp fall in women’s submissions of manuscripts to professional journals while ‘working from home’, as well as the disturbing feature of Australia’s economic stimulus package in response to the pandemic whereby spending on universal free day care was reduced to enable public spending on construction to increase (Cave, 2020).

In some cases, innovative and positive new approaches have been adopted that may continue after the crisis has passed (Kaserje and Kaserje, 2020). As existing models, practices and assumptions about how care should be delivered – for people with long-term disabilities and chronic conditions, or in child rearing and child development – proved inappropriate or inadequate, the political dimensions of caring were revealed afresh, raising questions for theory and research that invoke issues of power, agency and impact. To understand the lessons to be learned from COVID-19 about care, renewed questioning of the place of individuals and the political collective will be essential. Who is responsible for providing what type of care at what stage in the contagion process? For what are they responsible and under what conditions will they provide assistance? Who receives the care provided and how is that determined? How will different groups of care professionals and support staff respond if it is suspected that they are personally infected?

Epidemiological data on case numbers are clearly vital for identifying and responding to the spread of the disease, monitoring its incidence, and understanding its prevalence, yet their veracity is highly contested. The accuracy of COVID-19 reports is subject to measurement errors and weaknesses in data-collection systems, though questions also arise about deliberate political manipulation. Why, for example, were the deaths of older people, whether in care homes or at home, so often omitted from national

reports? Was the cause of death not reported because some cases had been deliberately excluded from diagnostic testing? Why were the gender and ethnic/racial backgrounds of patients not reported immediately, and why does the disease seem to mostly affect poor and vulnerable communities? The argument that official data collection is always political (Thompson, 2016; Piketty, 2020) seems particularly relevant in the COVID-19 case. Measurement also depends on accurate diagnosis – another area of dispute and contestation. Yet, in many countries, COVID-19 tests seem not to have been widely available, especially in the crucial period of disease growth, contributing to the distrust of authorities, especially among the already disadvantaged communities bearing the brunt of the illness.

Even the most accurate epidemiological data can serve to conceal the truth. Each person who dies of COVID-19 is a person who shared their life with others but whose passing is recorded primarily in numbers. This should cause us to reflect on why, as members of the human race, we care. We hold on to those we love, and learn to love those for whom we care. If care is to extend beyond a particularistic concern for individuals and become a universal ethic involving recognition of and concern for strangers, how should research respond? What lessons might we learn from the memorials, rituals of loss and celebrations of the lives of those who have died from the aftermath of COVID-19?

Finally, we need to understand in detail who gets sick in this pandemic, and who dies? Here, the larger political and economic questions that shape society are relevant. Access to outdoor public space, crowded living conditions, ill-ventilated public transport, who can observe ‘quarantine’ and who must continue to work – these and other socio-economic factors are part of the profile of this disease.

## Public health and the market

As Hochschild (1995; 2003) has argued, the concept of good care assumes different meanings under different social and historical circumstances and economic settings. Objective comparison of different approaches remains difficult when cultural and political assumptions shape how the concept of ‘quality care’ is regarded; however, the COVID-19 pandemic seems to provide new evidence of the success of some approaches to care and the failure of others.

Powerful and effective public health responses in some countries suggest that well-planned collective or public responses have been relatively successful in responding to these threats. These are seen in countries with diverse economies, governmental systems and histories. No current scheme of care regimes, welfare societies or comparative politics appears to predict where there will be success.

Innovation and efficiency have long been claimed as virtues that flow from the competitive processes of the market. Systemic solutions, such as privatisation and marketisation, have also been promoted as the necessary antidote to the problems of self-serving, inefficient and unresponsive public care systems (Hillmer et al, 2005; Pavolini and Ranci, 2008; Gingrich, 2011; Anttonen and Meagher, 2013). After over three decades during which the results of these different approaches have been studied and contested, the relative effectiveness of market-based and non-profit/public approaches in dealing with COVID-19 seems clear. We need a better way to characterise public health regimes and take account of care.

One example stands out: in the US, the number of cases, total number of deaths and death rate suggest that, even when expenditure on healthcare per person exceeds that in every other comparable country, the private healthcare system failed to prevent and to treat COVID-19 (WorldoMeter, 2020). As costs in the US increased the moment shortages became apparent, the absurdity of relying on the market for COVID-19 testing and for personal protective equipment (PPE) provided a powerful illustration, early in the pandemic, of the implications of the failure of markets (Luhby, 2020; Radcliffe, 2020).

Strong public health responses were not incompatible with a vigorous private care sector or a strong mixed economy. Indeed, that mix is clear in several countries where early public health intervention was effective in containing COVID-19 (WorldoMeter, 2020). However, in each case, it seems that the public health component of the response was clearly separated from medical care/clinical and social care provision, as well as from the ‘healthcare’ or ‘medical care’ system.

## Original research on COVID-19 and care

Despite a surfeit of passionate journalism – often termed the ‘first draft of history’ – inspired by COVID-19, serious and critical research addressing the challenges posed by the pandemic for how we understand care and its possible future has yet to emerge. In this edition of the *International Journal on Care and Caring*, we call for new papers for a special edition, to be published in 2021/22.<sup>2</sup>

It would be premature, and out of place, for us to specify topics or types of research. In our view, the scope for conceptual and empirical research is considerable, as the broad sets of questions we outline in the following indicate. These reflect basic conceptual issues and matters of theoretical significance, and suggest a need for clear thinking about how care and caring are defined, measured, documented and analysed:

1. *How should we identify and count care, both during and after the pandemic?* The work of caregivers in the healthcare, childcare and eldercare sectors is, self-evidently, ‘care’. Yet, the boundaries of even this care work are contested. Should, for example, the contributions of physicians and surgeons be included? Is the work of public health officials, health planners and healthcare managers in scope?
2. *What can we learn about the work of other ‘essential’ workers, such as those identified earlier in this article?* Does ‘essential’ work include unpaid work at home?
3. *How might the division of labour based on the exploitation of casualised employees and global care chains be reshaped in a post-COVID-19 world in which international mobility can no longer be assumed?*
4. *What can we learn about the process and social distribution of care in its different forms?* How does a pandemic change, or reinscribe, traditional patterns of care? In what respects are gender, class and/or race/ethnicity significant? How has the pandemic affected cross-national movements of migrant care labour, and the perceptions of these? Will the changes seen be merely short-term or transformative? What trade-offs may ensue?
5. *A feature of the global pandemic in many countries has been the sense of a shared ‘collective’ experience, common responsibility and mutual concern.* Will this sense of unity – that ‘we are all in this together’ – last? Was it real or ‘manufactured’? Will it break

- down as the pandemic subsides and competitive economic activity returns? If so, what will replace it?
6. *How do societies, moral philosophers and policymakers think about the value of care, and how does care fit (or not) into existing political frameworks?* To what extent do party platforms address care in any systematic way?
  7. *If care is fundamentally relational, what challenges does this pose to our ways of thinking in the social sciences, in training professionals and in approaching unpaid care provided at home?* Will the experience of care as a primary concern in households affect the nature of care relationships in the future? If so, how?
  8. *Do pandemics just appear or do they grow out of the conditions in which people live?* This involves thinking with and beyond epidemiology, to how virology and public health intersect with social life, politics and climate and environmental change. Which disciplinary approaches to research are needed to understand and think about ‘the unthinkable’?
  9. *Is there a better way to plan for the future?* This raises questions about global transmission and national and sub-national responses. Some nations have responded effectively but international coordination has been conspicuous by its absence.
  10. *How can we be attentive to the different levels of care?* At one level, having enough PPE seems a small matter of provisioning; yet, it was a critical issue in the COVID-19 pandemic. Which care needs were ignored and which must be quickly met? Are we doing this in the proper way?

## Conclusion: addressing the casualties of COVID-19

How can care become part of the achievement of a more just world, rather than a casualty of its injustices? Had all the global and national concerns of care been taken seriously before the pandemic struck, the outcome in many countries would, we believe, have been very different. This is an untestable hypothesis but our shared experience as survivors means that we have a unique opportunity to address the issues raised by the pandemic. Can we develop and undertake research about this global disaster from which we can learn, honouring its victims by treating the evidence it leaves in its wake as a ‘natural experiment’? Can we use the opportunity to make matters of care, both large and small, more central to how we allocate values and resources, as individuals, as societies and as a global community?

The call for papers accompanying this editorial article aims to generate a showcase of outstanding original research that draws on data collected during, or concerning, the pandemic, using these to interrogate how care is practised, misrepresented and ignored. It is an invitation to think deeply, possibly in daring new ways, about what care is and how care provisions are currently organised, and to learn from the experience of what has worked and what has failed in the ‘real world laboratory’ the COVID-19 pandemic presents. There are few opportunities to benefit from experience as powerful and universal as the events of the past six months. We welcome proposals, new approaches to theory and informed reflections in the hope that, while predicting world events remains beyond human capacity, we can do much to deepen and improve current understanding about care, and of the practices of care and caring, in our world.

## Notes

<sup>1</sup> In the US, for example, from 2016, President Trump and Congress cut funding to the Center for Disease Control (CDC), reducing the capacity of the government to undertake disease control activities domestically and internationally, see: [www.the-scientist.com/daily-news/cuts-to-prevention-and-public-health-fund-puts-cdc-programs-at-risk-30298](http://www.the-scientist.com/daily-news/cuts-to-prevention-and-public-health-fund-puts-cdc-programs-at-risk-30298) and <https://time.com/5177802/cdc-budget-cuts-infectious-disease/>

<sup>2</sup> Once they have cleared academic peer review, we will fast-track online versions of accepted articles.

## Conflict of interest

The authors declare that there is no conflict of interest.

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