

# Evidence in Times of Crisis

In a highly critical review of Carl Zimmer's *A Planet of Viruses*, Carr (2021) poses an important question: 'Is science a single, universal process that stands apart from struggles for power and resources – aka politics? Or is science the name for multiple processes, undertaken by different groups of people for different goals, all conducted in the very trenches of political struggle?' Among Carr's misgivings about *A Planet of Viruses* is that it tells half a story – the half that is devoid of politics. For instance, 'we learn how pathologists figured out that HIV comes from a primate virus', but not why so many gay people died from AIDS. What role did actors other than the virus play in this process – for instance, the Reagan administration's decision to block federal funding for HIV research? Likewise, Zimmer's account of the almost complete wipeout of Native Americans by smallpox attributes this disaster to the natives' 'immunological naivete with respect to the Europeans' accidental viral transmission', ignoring extensive scholarly work which maintains that it was essentially 'the violently imposed infrastructures of settler colonialism' that created the conditions within which the smallpox pandemic emerged and spread.

Meanwhile, the coronavirus (Covid-19) crisis that has engulfed all societies and dominated our thinking since the end of 2019 has placed the relationship between science and politics at centre stage. The repeated claim by many political leaders that they are 'following the science' as they make decisions that affect the lives of millions of people has come under attack for various reasons. Smith (2021) argues that this claim discourages citizens from thinking for themselves, because it suggests that science speaks with one voice; that it is a monolith; and hence that there is no room or need to debate its findings. But clearly science does not speak with one voice. It also rarely offers unequivocal answers, and its findings require time to verify. Cayley (2020) further suggests that viewing science as a monolith disables it, turns it into 'a pompous oracle that speaks in a single mighty voice', and at the same time 'cripples policy':

Rather than admitting to the judgments they have made, politicians shelter behind the skirts of science. This allows them to appear valiant – they are fearlessly following science – while at the same time absolving them of responsibility for the choices they have actually made or failed to make.

Policy responses to the identification and rapid spread of the highly mutated severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) variant Omicron in November 2021 brought the tension and entanglement between science and politics into sharp focus. While politicians responded to this new threat by imposing extensive border bans, especially on flights from African countries where the variant was first identified and where it was assumed to have originated, scientists disagreed about the efficacy and timing of such

measures. Some maintained that it was too late to impose such bans as the variant had already been identified in numerous countries and was circulating globally within days of it being reported by South Africa. Others argued that targeted border controls might discourage countries from reporting future variants. Others still pointed out that restrictions on commercial flights disrupt scientific work by blocking the transport of laboratory supplies needed for sequencing, hence impacting the speed with which new variants may be investigated. On 2 December, less than two weeks after the first travel bans were announced, a bioinformatician in South Africa told *Nature*: ‘By next week, if nothing changes, we will run out of sequencing reagents’ (Mallapaty 2021). And finally, recalling the issue of the entanglement of science and politics raised by Carr (2021), an article published in *Al-Jazeera* on 6 December argued that the bans on South Africa and neighbouring countries ‘do not reflect a sound public health policy’ but rather reveal the persistence of a colonial mindset that continues to shape the relationship between Europe and Africa (Kagumire 2021). Tilley (2020:161), on whose research the *Al-Jazeera* article draws, recalls that by the early twentieth century European colonizers had subjected many African cities to ‘race-based segregation strategies’, informed by germ theory, that were defended on the basis that they would ‘keep “white” officials healthier and separate them from infected African “carriers”’. The colonial overtones of medical and political practices continue to haunt us and challenge the idea that science and politics are two separate realms.

This book views science as inevitably and inextricably embedded in a multitude of narratives such as those told by Zimmer, Carr, Kagumire and numerous others, both scientists and non-scientists. We acknowledge, moreover, that scientific claims are themselves narratives, and that whatever their factual status, they are ultimately assessed on the basis of people’s lived experience and the values they hold most dear. We try to tell multiple stories from a variety of perspectives and offer a theoretical basis for understanding how different individuals and communities decide which of a range of competing stories they should believe in and why. The theoretical framework we apply assumes that understanding intricate scientific details is not an innate skill, but telling and assessing narratives is. If it wasn’t, none of us would be able to engage with the multitude of stories that make up our social world or make decisions about how to act, and on what basis. While accepting that scientific evidence has a key role to play in shaping public policy and should – in an ideal world – be taken seriously by members of the public, we demonstrate through numerous examples that it is often mistrusted and/or overridden by considerations that are affective and social in nature. These considerations, in turn, are informed by the narratives to which we are all socialized over many years and in numerous contexts.

The Covid-19 crisis offers many resonant examples that allow us to flesh out and demonstrate the theoretical principles that inform our arguments. But the scope of our argument is much broader than Covid-19, and broader even than pandemics as such. In developing an approach to medical knowledge that can account for the way both experts and non-experts make sense of what constitutes reliable evidence in various contexts, we are not merely concerned with the *science* of Covid-19 or pandemics but with the myriad discourses in which different narrators articulate their understanding and evaluation of different types of evidence, whether or not they draw on scientific sources. Our point of departure is Walter Fisher’s distinction (outlined in Chapter 2) between the world as ‘a set of logical puzzles that can be solved through appropriate analysis and application of reason conceived as an argumentative construct’ (Fisher 1987:59), and the world as ‘a set of stories that must be chosen among to live the good life in a process of continual recreation’ (Fisher 1984:8). We

engage with this distinction specifically as it plays out in the field of medicine, and in the recent Covid-19 crisis, but we believe that it provides a helpful point of departure in examining many other areas of social and cultural life. Rather than treating various practices of knowledge as rational or irrational in purely scientific terms, we attempt to understand the controversies surrounding Covid-19, as a case in point, by drawing on a theoretical framework that recognizes and explains different types of rationality, and hence plural conceptualizations of evidence.

Some of the issues we raise are exemplified by the controversy reported in *The New York Times* in August 2020 under the title ‘The Covid drug wars that pitted doctor vs doctor’ (Dominus 2020). The question which ‘opened up a civil war’ between clinicians drawing on their experience to save lives and medical researchers who believe that ‘[r]elying on gut instinct rather than evidence . . . was essentially “witchcraft”’ is: ‘How much freedom should front-line clinicians have in treating Covid-19 with unproven drugs’. The *New York Times* report, which involved interviewing several clinicians, reveals that the issue is much more complex than the question suggests. Even physicians who had been committed to relying on evidence from randomized controlled trials (RCTs), according to colleagues, wanted access to all types of unproven medicines when it was their mother fighting for her life. For decisions that directly affect us or our loved ones, scientific evidence may be largely overridden by other considerations, even for those who would otherwise appeal to it as the only rational basis for decision making.

## 1.1 The Status of Evidence in Evidence-Based Medicine

The Covid-19 crisis has transformed the highly specialized issue of what constitutes reliable medical evidence into a topic of public concern. Newspapers and social media abound with discussions about whether the evidence for wearing masks is weak or strong, or whether mass public health measures such as lockdowns or school closures are backed by sufficient evidence. At the same time, a global initiative for gathering evidence to support the development of new, more effective vaccines and drugs continues in laboratories and clinics that are far removed from these sites of public debate and from the immediate pressure of delivering healthcare in emergency situations. Underpinning all these different discussions about and approaches to evidence is a shared assumption: that evidence is singular and that it can be ranked on a singular scale as present or absent, strong or weak, from a purely rational, value-free perspective. This book interrogates the assumption that evidence means the same thing to different constituencies and in different contexts by outlining a more nuanced and socially responsive approach to medical expertise that incorporates scientific and lay processes of making sense of the world and deciding how to act in it. In so doing, it hopes to provide a point of orientation for clinicians working at the coalface, whose experience is sometimes at odds with the type of rationality that underpins evidence-based medicine (EBM) and that guides researchers conducting RCTs. The argument elaborated also has implications for policy makers in the healthcare system, who have to navigate similar pressures and contradictions between scientific and lay rationality to produce meaningful guidelines in the midst of a runaway pandemic.

While using Covid-19 as an exemplary case study, this book takes as its point of departure the premise that the controversies surrounding the nature of evidence were also present in earlier epidemics such as SARS and Ebola virus, and that they will continue to plague our responses to future pandemics unless we learn to address them more effectively.

Pandemics in general, and Covid-19 in particular, are emblematic sites for exploring and challenging concepts of evidence because they clearly transform such concepts into a topic of public concern and demonstrate the relevance and urgency of engaging with the processes by which they come to be understood and assessed differently by various constituencies.

In medicine and healthcare, the EBM paradigm, which started to emerge in the 1990s, has contributed to promoting an understanding of evidence as a singular phenomenon that can be ranked on a singular scale. According to Sackett et al.'s (1996) much cited definition, EBM is 'the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients'. In line with this programmatic statement, EBM has emphasized the use of clinical guidelines and challenged clinicians to question their reliance on pathophysiological reasoning and unenhanced clinical judgement. Clinicians are now trained in reading research literature and converting the findings from published studies into probabilities based on mathematical estimates (Solomon 2015). Accordingly, the EBM movement has developed mathematical and experimental techniques for producing and evaluating evidence, including statistical meta-analysis of research results and methods for developing and implementing clinical guideline recommendations.

The framework EBM developed for ranking evidence rests on a hierarchy that features simple observational methods at the bottom and moves on to increasingly rigorous methodologies, notably comparative experimental intervention studies, RCTs and systematic reviews of such trials at the top of the evidence pyramid. Although this hierarchy has been criticized and modified, a dominant assumption among EBM advocates is still that findings generated by RCTs are likely to be 'closer to the true effect than the findings generated by other research methods' (Evans 2003:78). Epistemologically, the EBM hierarchy relies on observations (empiricism) as the method of knowing; ontologically, it conceives of reality as a set of causal mechanisms (realism) (Greenhalgh et al. 2014; Engebretsen et al. 2016). But as the Covid-19 crisis clearly illustrates, there are many sites of knowledge construction in medicine – let alone other spheres of practice – where these rules do not apply. Recovery stories, for instance, are intended to give voice to the patients' perspectives and draw on an experienced reality rather than empirical findings, while a policy brief aims to provide strategies and points to a reality of ideas and visions rather than of embodied practices. While also engaging with the type of knowledge elaborated in discourses such as policy briefs and patient statements, the EBM evidence hierarchy only acknowledges one single concept of evidence, that is, 'close to the true effect'. Hence, the EBM conception of knowledge fails to acknowledge that the way different groups engage in the process of knowing – as articulated in different types of discourse – determines the principles and objects of their knowledge.

The narrative framework that informs our analysis of how medical researchers, medical practitioners, policy makers and lay people conceptualize and evaluate evidence recognizes that 'human beings are as much valuing as they are reasoning beings' (Fisher 1997:314). In outlining and extending this framework, we seek not only to interrogate current, restricted conceptualizations of evidence in the EBM model, but also to elaborate a more socially responsive approach to expertise that can offer insight into the sources of controversy around medical phenomena such as Covid-19 and a more productive approach to addressing them and communicating medical information without unduly antagonizing large swathes of the population. The scheme we offer is largely diagnostic, although we argue in Chapter 6 that we also have a moral responsibility to introduce creative possibilities in our

interaction with others by constructing narratives that “provoke intellectual struggle . . . and the creation of a more workable human order” (Bennett and Edelman 1985:162; Baker 2006:163). As far as medical controversies are concerned, we do not offer recommendations but rather a model of analysis that can shed light on why different people arrive at different decisions based on the same sources of evidence, and why we must acknowledge their reasons for doing so as rooted in different types of rationality rather than dismissing them as irrational. Ultimately, as Fisher (1987:113) explains, the purpose of the narrative paradigm we apply throughout this book is ‘to ensure that people are conscious of the values they adhere to and would promote in rhetorical transactions, and to inform their consciousness *without dictating what they should believe*’ (emphasis in original).

This book shares some of the theoretical assumptions of narrative medicine, but it also differs from the large body of scholarship in that field in important ways. While narrative medicine is mainly concerned with clinical practice, the model we introduce extends to the daily lives of all citizens and the way in which knowledge based on medical evidence is accepted or rejected by all members of society. On a conceptual level, our approach does not rely on the distinction – inherent in narrative medicine – between narrative medicine as the ‘art’ and EBM as the ‘science’ of medical practice (Solomon 2015:178). From the perspective of the narrative paradigm, EBM is embedded in a multiplicity of narratives and hence is itself ‘an interpretation of some aspect of the world that is historically and culturally grounded and shaped by human personality’ (Fisher 1987:49). Importantly, we do not reject the EBM paradigm, nor do we suggest that it should be replaced by the narrative paradigm. We merely argue that – from the perspective of the narrative paradigm – the empiricist notion of evidence underpinning EBM is only one possible situated interpretation or value according to which knowledge claims can be and are in practice assessed. This means that the narrative paradigm is not a practical tool for improving medicine but rather an epistemological tool that reveals the values on the basis of which we assess stories and claims of evidence. By contrast with the narrative paradigm framework proposed here, narrative medicine does focus on improving medicine and is fundamentally linked to the idea of caring for the individual patient. Solomon (2015) distinguishes four general aspects of narrative medicine as it has evolved since the late 1980s: (1) listening and attentiveness to the patient’s story and point of view; (2) empathy or experiential understanding of what the patient is going through; (3) detective work or attention to the explicit and implicit contents of the patient’s story; and (4) meaning making or the act of making sense of the patient’s sufferings through storytelling, for example through narratives of restitution, chaos and redemption (Frank 1995). Our aim is different: we draw on and adapt the narrative paradigm in order to provide a framework for understanding how we assess different narratives on the basis of the values we believe each encodes and the extent to which they resonate with our own values and beliefs.

## 1.2 Organization of Chapters

Chapter 2, ‘Narrative Rationality and the Logic of Good Reasons’, outlines the main tenets of the narrative paradigm, acknowledges critical scholarship relating to its applicability in some cases and settings, and demonstrates its usefulness through a variety of examples from different areas of controversy that arose during the Covid-19 pandemic and are dealt with in more detail in chapters 3, 4 and 5. The chapters that follow do not only explain different antagonisms surrounding Covid-19 from the perspective of the narrative

paradigm as elaborated by Walter Fisher, but also extend the framework. They nuance the narrative paradigm in the course of analysis, especially with reference to its application to medical narratives and its potential for offering a point of orientation for medical practitioners and policy makers in the healthcare sector.

Arguments about the pros and cons and possible effectiveness of face masks have occupied considerable space in specialist, medical venues such as peer-reviewed journals and science blogs as well as public forums such as mainstream media and social media – the latter attracting contributions from medical specialists and lay members of the public alike. The debate has often been heated, and there have also been reports of individuals resisting the stipulation to wear face masks in shops and on airplanes, at times leading to acts of physical violence. Drawing on the theoretical model outlined in Chapter 2, Chapter 3, ‘Whose Evidence? What Rationality? The Face Mask Controversy’, examines some of the arguments for and against face masks as articulated by a diverse range of individuals and constituencies, within and beyond the Anglophone and European world, and the justifications given in each case, as well as the underlying values and logics of these various parties.

Chapter 4, ‘Whose Lives? What Values? Herd Immunity, Lockdowns, and Social/Physical Distancing’, examines disagreements about mass public health measures such as lockdowns and physical distancing, which have dominated discussions around Covid-19. Policy-oriented discourses such as recommendations and media briefings have argued for more or less severe measures, ranging from national curfews to mandated physical distancing (unfortunately termed social distancing) or mitigation strategies built on the premise of quickly reaching herd immunity. All these different measures have been extensively debated in the media and other public forums and continuously monitored by international organizations such as the World Health Organization. Policy arguments have also been revised or refocused in tandem with a growing body of research and natural experiments as countries began to introduce either mandatory or voluntary policies. Chapter 4 examines various arguments deployed in this debate and the complex dialogue between political, scientific and popular values and discourses.

Chapter 5, ‘The Rational World Paradigm, the Narrative Paradigm and the Politics of Pharmaceutical Intervention’, examines some of the rationales for pharmaceutical interventions, especially vaccines, and resistance to them. Vaccine-hesitant and anti-vaccine activists have questioned different aspects of the Covid-19 vaccination programme, and some have even argued that the whole virus is a scam and part of a plot to profit from selling vaccines. The discussion regarding vaccines and other potential pharmaceutical treatments quickly became highly politicized, especially after Donald Trump’s official endorsement of the malaria drug hydroxychloroquine. The debate about vaccines and treatments does not only reflect tensions between science and politics and expert and non-expert discourses. It also highlights the fact that there are divergent views within the scientific community itself on when new evidence may be ready to be put into political action. Chapter 5 explores the divergent arguments used in this debate as well as their various and complex value-laden underpinnings.

In the final chapter, ‘Objectivist vs Praxial Knowledge: Towards a Model of Situated Epistemologies and Narrative Identification, we revisit some of the tenets of the narrative paradigm, based on the analyses presented in the preceding three chapters, and suggest ways in which the concept of narrative rationality may be further developed and nuanced. Fisher distinguishes between objectivist knowledge and praxial knowledge, and argues that it is the

latter type of knowledge that narrative rationality seeks to ‘foster and support’ (Fisher 1994:26). The aim of Chapter 6 is to use this distinction as a starting point to develop a model for situated epistemologies based on insights drawn from Fisher’s narrative paradigm, proposals put forward by some of his critics and the work of thinkers such as Heidegger and Kristeva, together with more recent work on narrativity.