



CRITICAL STUDIES IN RISK AND UNCERTAINTY

Experiences of Health Risks

Prevention, Power Dynamics
and Inequalities

Claudine Burton-Jeangros

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To Tony

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1

Introduction: Experiences of Health Risks

The idea of risk has gained widespread influence on how we live. Individually and collectively, in official and mundane activities, risk has become a catch-all concept expected to guide actions toward averting unwanted future situations. Probabilities, as a cognitive tool developed by statisticians, are constantly used to anticipate the future. The appeal of these predictions is supported by widespread aspirations for control over adverse events. Nevertheless, if risk started to shape the social fabric of societies several decades ago, its ambition to improve society and people's circumstances keeps being challenged.

If for many, risk is a tool that should generate undisputable consensus over how to act, the assumption that knowing more about risks is necessarily beneficial can be challenged at the light of the societal disputes regularly generated by the anticipation of harm. Indeed, risk is a profoundly normative concept. It is used to regulate social activities, to allocate resources to some anticipated harm while it denies or misses other threats. In this book, I argue that recurrent debates about risk exist because most of the time the notion leaves aside the complexity of social processes surrounding actual experiences of vulnerability and danger in society.

Some general features of the idea of risk are important to sketch upfront as they contribute to the tensions taking place around the regulation of adverse events. First, risk is intangible. It is a discourse, or a mental construction, about what is likely to happen. It is a prediction based on regularities observed on past experiences. Once misfortune takes place, it is not considered a risk anymore, but it is framed as an event, a catastrophe, a disease, or death. The pervasiveness of risk, as an abstract entity existing only in terms of predictions, illustrates well the fact that we live in a post-industrial context, in which information or knowledge is central. Reflecting the overall quantification of social life, risk probabilities are expected to play a prominent role in the conduct of human lives. However, multiple filters affect both their formulation and their application to real-life circumstances.

Second, risk is tightly associated with the ambition to control future events, as formulated by Bernstein: “The revolutionary idea that defines the boundary between modern times and the past is the mastery of risk: the notion that the future is more than a whim of the gods and that men and women are not passive before nature” (Bernstein, 1996, p. 1). Predictions based on risk calculations are associated with thresholds, standards, and recommendations to guide individual and collective actions across various scenarios, defined as more or less desirable. The authority of science is used to formulate a single course of action that should be consensually preferred. However, depending on their multiple relations with the situation and their other commitments, people often do not agree on what is best and who should be accountable for danger.

Third, there is a profound contradiction between risk as a tool designed to elaborate decisions enhancing collective security through cost–benefit analyses and the promotion of individual responsibility in the modern context. Predictions help to estimate what is likely to happen across a number of people or places and can thus support governments and institutions in policy-making. Considering that adverse events will occur, risk pooling generates solidarity across a group of people to support those who will incur loss. However, the application of probabilistic risk reasoning at the individual level or for single cases is not operative, regardless of the odds of disease, death, or catastrophe. Individual autonomy and collective risk regulation are thus not easy to combine.

Fourth, risk introduces a disconnection between increased expectations of safety and persistent experiences of harm. Risk has indeed brought many benefits, as assessed by a range of social, economic, and health indicators. However, predictions are constantly challenged by unexpected crises, unforeseen events, or low-probability accidents. From the Chernobyl accident in the 1980s to the recent COVID-19 pandemic, the repetition of crises in multiple forms and domains keeps questioning the promises raised by risk management. This disconnection contributes to discrediting the very idea of risk and the trust that experts and institutions had gained over the first part of the twentieth century.

By asserting that nothing happens by chance, risk profoundly impacts society. However, risk only provides a map, reducing the complexity of the world to a limited number of dimensions. Risk is not the territory, the actual conditions in which people experience illness, suffering, and misfortune. My aim is to discuss this tension.

On the one hand, conventional or formal risk management, supported by the increasing capacity to predict harm for human lives and their environments thanks to risk probabilities, has developed a generic model to control the adverse consequences of anticipated threats based on cost–benefit trade-offs. The characteristics of this model include notably being top-down, intellectual, abstract, rational, and quantitative. It gained legitimacy in organizing human activities in the best collective interest and progressively expanded across all life domains. However, its promises remain constantly challenged by its difficulty in fully anticipating threats—which risks should be measured?—and societal reactions—how will people respond to forecasted danger?

In this book, I propose to focus on ‘experiences of health risks’ to better understand how people domesticate their personal vulnerability, including material, affective, symbolic, and interpersonal elements. This approach considers that they have to turn the abstract or elusive category of risk into something that they can relate to and therefore may act upon. Indeed, risk brings discontinuity or disorder, questioning aspirations for continuity in social life. Thus, people have to integrate unforeseen danger into their routines, possibly revisiting these or accepting them despite them being labeled dangerous. In addition, they make connections with tangible elements, such as their past experiences, their personal conditions, or current societal concerns to gain some grip over this unsettling

idea. Being interested in experiences of risk implies to consider these within their related institutional environments which, beyond information, provide rules and recommendations, possibly sanctions. In addition, these experiences are shaped by constant interactions with others, who in their different social roles—as relatives, friends, or professionals—validate some risk interpretations and actions while they devalue others. These relations can generate both conflicts and alliances among people facing potential harm.

In relation with my own research, I focus my attention on people's experiences with regard to health risks, a domain in which risk expansion has been particularly prolific, from individual genetic risks to global pandemic risks. In recent decades, health has indeed gained much scientific, mediatic, and societal attention. Continuous gains in postponing death triggered interest in the anticipation of disease and the promotion of health. Health, as experienced in individual bodies, is situated at the crossroad of biological, social, and political processes. It thus occupies a number of disciplines analyzing it under their specific lenses. As a sociologist, I am interested in the multiple and multifold social processes taking place around health issues. In the context of the HIV/AIDS epidemic, the stigmatization of infected persons early on was considered a challenge as large as the diffusion of the virus. More recently, the World Health Organization warned that the infodemic surrounding the COVID-19 pandemic was as much a threat as the virus itself. These two examples show how risk probabilities have social consequences.

I aim to show how the social sciences contribute to the understanding of health risk prevention. Following Mol (1998), who considers pathology to be a lived reality, or Kleinman (1978), who asserts that illness is the lived experience of disease, I focus my attention on the lived reality of health risks. In addition to being an abstract prediction, being at risk has concrete implications for people's lives, questioning their confidence in their own bodies and their capacity to fill their social roles. In the health domain, science and medicine play important roles, as their position often prevails over others. Their perspective is pervaded by a narrative dominated by a number of assumptions, including scientific reason as a straightforward precursor to collective solutions, people as maximizers of their own interest in every circumstance, and a specific set of values. However, examining experiences of health risk and uncertainty unveils

the situated character of prevention campaigns, their underlying power dynamics, and their relations with health inequalities.

My goal is to understand how people in diverse positions, as members of the general public or professionals, actually think, act, and interact around experiences of risk. Influential scholars, such as Beck (1992), Douglas (1985, 1995), Ewald (1986), and Giddens (1990, 1991), have described the social transformations leading to the emergence of modern risk culture(s). However, their thinking has remained mostly abstract, and here, I wish to connect the social theories of risk propositions with empirical studies focused on health risk experiences. These studies help describe the challenges people encounter when they try to make sense of risk, while taking into account the social influences that affect their reactions.

To better understand how people actually handle health-related risks, I address the following questions in the upcoming chapters. In Chap. 2, how do people make sense of risks through multiple forms of knowledge? In Chap. 3, what is the role of emotions associated with risks? In Chap. 4, how are actions adopted to respond to risks justified? In Chap. 5, how is risk prevention shaped by moral judgments in social interactions? In Chap. 6, how do social structures expose and protect individuals differently? In each chapter, a first part brings together theoretical elements, starting with sociological theory, followed by social theories of risk and sociology of health insights. The second part presents empirical findings to illustrate recurrent challenges across risks and contexts. I mostly discuss health risks in affluent countries, but I sometimes adopt a broader scope such as when addressing re-emerging infectious diseases. Attention is given to studies focused on members of the public but also to the role of professionals in institutions, to emphasize how health prevention takes place amidst relations, characterized by consensus or conflicts depending on the issues tackled.

The COVID-19 pandemic clearly revived societal debates about risk, uncertainty, precaution, mobilization of science, and resistance to experts' views. These recent debates only expanded questions that have already been present for a while. In this book, I follow health risks over time and settings to document contrasting experiences attached to them across society.

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2

Knowledge, Uncertainty, and Ignorance Around Health Risks

Introduction

Risk is associated with science as a dominant institution in modern societies. Formal risk knowledge, based on scientific reasoning, is expected to guide human action in a wide range of domains with the intention to avert future harm. The capacity to calculate odds, valued by experts and institutions, is associated with the prevention of risks as a widely shared principle for the organization of individual and collective lives.

Challenging the assumption that the expansion of formal risk knowledge is necessarily beneficial, I describe in this chapter how social contexts matter in the production, circulation, and reception of such knowledge. Risk as an abstract idea raises attention before harm is actually present. At the same time, it highlights the extent and permanence of uncertainty, namely, what is not yet known or even knowable. These features of risk evidence are prone to generate controversies in society. In addition to the increasing awareness of difficulties in estimating probabilities that can help predict future misfortune, making sense of the constantly increasing amount of risk knowledge is challenging. This chapter intends to show how, over the past decades, the proliferation of the idea

of risk has contributed to transforming the relationships between science and society in general and to undermining the authority of formal or quantitative knowledge.

Across a range of health risks, including lifestyles, genetic or cancer screening, exposure to environmental threats, and infectious diseases, formal risk knowledge is constantly extending with the development of biomedical and epidemiological research. At the same time, this extension continues to create new concerns. In addition to the difficulties reported by people who have to make decisions based on predicted risks, the logic of risk continues to expand the scope of possible actions. Consequently, it creates opportunities for conflicts across contrasted views about the best ways to promote and protect health. In addition, influences affecting the production and circulation of knowledge, or its manipulation to serve situated interests, suggest that multiple social filters affect how risk knowledge is conveyed in the elaboration of recommendations to protect individual and public health.

I am interested in how social actors, across their different positions and circumstances, praise, challenge, complement, or manipulate tools offered by probabilistic thinking. Against efforts of science to delimit and establish solid facts on possible threats, thus usually looking at them as isolated problems, social actors constantly navigate across a number of health issues. They are regularly confronted to these at their own personal level or as these issues affect people they know, but also to global threats debated across multiple communication channels. By discussing a number of situations, defined as public health or clinical risks, in their real-life application, I am interested in how the shortcomings of formal health risk knowledge contribute to a questioning of the value of science.

In the first part of the chapter, I present elements of sociology of knowledge and social theories of risk to sketch the background against which the evidence about health-related risks has widely expanded. Then, using empirical illustrations from a range of health domains, I discuss how knowing about risks is generating multiple challenges at both the individual and collective levels.

Risk Knowledge Applied to Health

Sociology of Risk Knowledge

For social scientists, the production of knowledge is not a natural and universal process of accumulation that goes unchallenged. Rather, they are interested in what counts as knowledge, whose claims are considered most relevant, and how knowledge circulates in society. This means that the status of different forms of knowledge varies across contexts, reflecting social hierarchies and shaping expected interactions across social groups (Berger & Luckmann, 1991 [1966]). In this section, I first revisit how probabilistic thinking became so dominant and how its success was approached by social scientists.

The Scientific Approach to Risk

In the process of disenchantment of the world described by Max Weber (1964 [1904]), science—or formal knowledge—took over the role previously played by religion and magic in sense-making. Modern secular societies favor explanations of the environment and human activities based on experimentation, systematic data collection, and analysis. These techniques are expected to produce knowledge that evacuates unexpected and mysterious forces and offers control over events (Weber, 1963 [1919]). Dismissing the value of common-sense knowledge, scientists focus on regularities to formulate abstract generalizations. Over the Enlightenment process leading to a rationalization of natural and social life, science has become an authoritative system of knowledge. This implied formulating claims of a ‘universalized truth’ valid at the worldwide scale, independent of local circumstances (Swidler & Ardit, 1994). This was made possible by the existence of institutions and people who gained sufficient authority in establishing the truth and in arbitrating disputes. Since science started to define what is actually thinkable, Michel Foucault (1989 [1966]) associated such authority with power. In modern societies characterized by functional specialization and rationality, science turned into expertise summoned to guide the organization of social life. Its dominant

position was initially reinforced by the limited circulation of formal knowledge, whose access was restricted through dedicated channels and closed to the general public.

Through systematic observations of the past and the development of statistical tools, science progressively became a dominant institution in the management of the future through risks calculated as probabilities offering quantified measures of the likelihood of specific events (Bernstein, 1996). In risk management, preventive actions are defined as the joint evaluation of the probability of an event and its expected consequences (Aven & Renn, 2009). Cost–benefit analyses define possible interventions as a trade-off between positive and negative consequences of any activity. Turning past unspecified dangers into calculable risks (Castel, 1983) led to major improvements in safety and security in all systems supporting people’s lives. The capacity to calculate risks and thus to predict adverse events was crucial in the development of compensation mechanisms through insurance and welfare systems (Ewald, 1986). Over the course of the twentieth century, risk analysis has been increasingly and systematically summoned to govern all human activities, such as public transport systems, nuclear plants, and everyday mundane activities, as well as a tool for the regulation of public institutions. Over the past century, formal risk knowledge has become ubiquitous and self-evident, and the identification of potential threats turned into a key pillar of individual and collective action. It follows an overall taken-for-granted quantification of social life, to which considerable social and intellectual resources are allocated (Espeland & Stevens, 2008).

Following the growing success of a probabilistic view of the world, formal risk management is equated with reason and rationality. Experimental and quantitative research designs purposively reduce the complexity of the world to identify regularities that help to calculate risks and to act preventively on hazards. The dissenting views formulated by members of the public regarding the safety of technology and the impact of human activities on the environment, hence statements questioning science, have been attributed to a lack of rationality or to emotions, both of which are considered antithetical to modern society and to science. Studies on risk perceptions initiated in the 1960s (Slovic, 1992) attributed systematic gaps between experts and members of the public to the

latter's cognitive deficits. Considering human activities under the lens of the rational actor model, proper education of the public or risk numeracy was deemed the solution to eliminate this gap and to reach social consensus over risk issues (Leiss, 1996). Risk communication, set up as a component of risk management, was then conceptualized as the last stage occurring after scientific and technical processes, aiming at informing and convincing the general public or specifically concerned groups about relevant actions to reduce risks.

Over the twentieth century, formal risk knowledge driven by faith in progress and science had a massive impact on society's organization and cultural background. Through the elaboration of guidelines, thresholds, recommendations, risk management broadly affected social norms by suggesting adequate ways to think and act toward the future. In addition, the ambitions of risk management fueled a zero risk narrative and a never-ending quest for safety: "in contemporary society, we can never feel safe or healthy enough" (Furedi, 2009, p. 217). Reflexive or post hoc assessments of action in light of available evidence often associate the occurrence of any unwanted event with human failure. While expanding insurance mechanisms provide protection against their negative consequences, each of these events still incarnates a missed opportunity for prevention. It most often leads to evaluations of the accountability of those—individuals in their private lives or officials in their professional positions—who should have averted the adverse outcome.

However, this dominant perspective, considering the future to be manageable and under human control, continues to be challenged by alternative ways to approach danger and uncertainty. Hence, recurrent dilemmas associated with risk management prompted developments in the social theories of risks.

The Social Theory Approaches to Risks

The growing influence of risk has led social scientists to scrutinize its impact on modern societies (Short, 1984). Amidst their diverse contributions, I focus here on elements related to the role of knowledge in risk management.

In his acclaimed book *Risk Society*, Beck (1992) contended that modern societies now have to address the management of the risks created by the developments of technology and science. He framed increasing social preoccupations toward nuclear energy and the environment as the result of manufactured risks, that is, those new dangers generated by the development of technologies in industrial society. With Giddens (1990), he emphasized the globalization of risks, alongside important socio-economic transformations occurring at the worldwide scale. As illustrated by the Chernobyl accident, such invisible and distant risks could only be grasped through mediated knowledge elaborated by specialists. Since then, widespread awareness of global risks has been sustained by analyses and guidance developed by international agencies, such as the OECD report on systemic emergent risks (OECD, 2003) or the annual report on global risks of the World Economic Forum since 2006 (World Economic Forum, 2023). In parallel, “risk profiling” started to cover increasingly everyday life and intimate spheres, including health aspects (Giddens, 1991), under the assumption that individuals would benefit from any information about the risks they are exposed to.

At the same time, this process of constant expansion of risk knowledge, inherent to scientific efforts, rendered visible the limits of what is known and shed light on what is not known (Beck, 1992). According to the distinction between risk and uncertainty, some events can be predicted based on existing data related to previous circumstances, while others cannot be quantified due to the absence of any past occurrence. This distinction, which was formulated by the economist Knight in the early 1920s, was overshadowed by rapid scientific progress and concomitant developments in risk management. Indeed, in the middle of the twentieth century, sociologists Moore and Tumin wrote, “Ignorance is commonly viewed today as the natural enemy of stability and orderly progress in social life” (Moore & Tumin, 1949, p. 787). Nevertheless, a few decades later, the social theories of risk emphasized the persistence or even extension of nonknowledge as a result of the constant expansion of science. Scholarship on uncertainty and ignorance (Gross & McGoey, 2015; Proctor & Schiebinger, 2008) developed to address the complexity of nonknowledge. In addition to attention given to uncertainty and hence to what is not known or knowable, social studies of science

contribute to risk scholarship by showing how knowledge is produced, or not produced in the case of ‘undone science’, while taking into consideration how it is influenced by social, institutional, and material contexts (Frickel & Vincent, 2007; Fujimura & Holmes, 2019).

On the one hand, nonknowledge refers to the absence of evidence itself: no scientific fact merely exists, as is the case with new dangers such as the HIV or COVID-19 viruses when they first emerged. The time needed to collect and analyze data suggests that knowledge and non-knowledge are not opposites but rather situated on a continuum that includes “partial, inexact, uncertain, provisional and uneven knowledge” (Heimer, 2012, p. 19). Indeed, the ever-increasing capacity to collect more data, to pool data across locations, and to analyze them supports the identification of further risks while simultaneously producing manufactured uncertainty (Beck, 1999). Partial and dynamic knowledge regularly places individuals in front of the obligation to make personal or collective decisions, while they know that their decisions will be revisited later in light of new knowledge. I refer to this as uncertainty.

On the other hand, nonknowledge relates to the lack of command over some facts by some people: evidence exists, but it is not known by all. This understanding emphasizes issues related to the circulation of knowledge at multiple levels. First, the ever-increasing specialization of scientists means that they are knowledgeable in narrower domains (Giddens, 1990) and thus struggle to keep up with existing evidence within and outside of their own domain of expertise. The difficulty of distinguishing between personal and collective ignorance is currently exacerbated by the continuously increasing amount of research produced and its rapid diffusion. Second, ignorance studies (Gross & McGoey, 2015) or agnotology (Proctor & Schiebinger, 2008) are interested in the role played by this form of nonknowledge in debates around risks. Here, nonknowledge is conceived as the result of different ‘social arrangements’ that can either passively end up in the absence of science or actively be produced when the intention to deceive others is present (Pinto, 2015). I refer to this as ignorance.

These social science developments show the transitory nature of formal risk knowledge and the multiple influences affecting its production and circulation. Considering its limited capacity to offer uncontested and