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The Uncertain and the Unruly: Complexity and Singularity in Biomedicine and Public Health*

The centrality of "risk" as an organizing theme of current descriptions of contemporary Northern Societies, especially in the wake of Ulrich Beck's concept of "risk society" (1992) and the debates it triggered, have had two noticeable effects. The first was the proliferation of forms of "riskspeak", with risk becoming a pervasive and sometimes unqualified way of referring to uncertainties, particularly those likely to generate events taken as adverse, damaging or otherwise undesirable. This, in turn, has led to a legitimation of expert re-appropriations of uncertainty as their turf, and of attempts to bring all sorts of uncertainty under prevision and rational calculation and control.

Definitions of risk may refer to the probability of occurrence of a given event in a population or subpopulation at a given time or during a given time period. It does not necessarily involve a qualification of the events in question as desirable or undesirable, positive or negative. This is the use we find in disciplines such as demography, where the notion of "population at risk" (e.g., women in childbearing age – 15-49 years – are "at risk" of conceiving) is routinely used in this "neutral" sense. But many, if not most of the

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technical definitions of risk tend to qualify the events they refer to as "adverse". For instance, in an authoritative statement about risk, the Royal Society defines the latter as "… the probability that a particular *adverse* event occurs during a stated period of time, or results from a particular challenge" (The Royal Society, 1992: 2; emphasis added). More generally, risk refers to a clearly identified hazard or threat, whose probability of occurrence can be determined within certain limits and under certain conditions (Callon *et al*., 2001). Identification of populations at risk, of specific events and of their probability of occurrence are thus common features of definitions of risk associated both with their evaluation and with their management, involving "the projection of a degree of uncertainty about the future on to the external world" (Heyman, 1998: 5). This definition, according to Heyman, "treats risk as a simplifying heuristic which can provide a useful guide to the action, but which can also systematically mislead" (id.)

It has been pointed out by different streams of work, however, that many of the situations routinely defined as falling under the umbrella of risk assessment and risk management display features which resist attempts to bring them under the kind of scrutiny and control usually associated with the latter. In a widely-used textbook on organizational theory, James March and Herbert Simon propose a clear distinction between two kinds of situations. In situations where *choices are possible*, and where "accurate knowledge of a probability distribution of the consequences that will *follow on each alternative*" is viable, these situations fall under the label of "risk". Where, however, "the consequences of each alternative belong to some subset of all possible consequences, but… the decision maker cannot assign definite probabilities to the occurrence of particular consequences", *uncertainty* will be a more adequate description of the situation (March and Simon, 1993: 137).

In general terms, we may say that in a situation of uncertainty potentially hazardous or dangerous events cannot be precisely identified or defined, nor a probability assigned to their occurrence or to the consequences of alternative courses of action. Uncertainty, in this sense, is a crucial feature of situations characterized by heterogeneous processes whose intersection gives rise to the emergency of complex, "unruly" and/or singular configurations. Precautionary action is usually associated with the management of situations of uncertainty as just defined.

It should be noticed, before we move on to the specificities of health and medicine, that the dominant model of cognitive-instrumental rationality encourages the interpretation of uncertainties as risks, thus "rationalizing problems previously outside the realm of systematic control" (Clarke, 1999: 11). This, in turn, has significant consequences for both the production of knowledge of specific situations and definitions of ways of acting on the situation. Whereas risk assessment and risk management are usually associated with preventive action, the management of uncertainty seems to be associated with precautionary action. I shall not get, here, into the debates on the definitions and qualifications of precautionary action or the precautionary principle which is invoked as its rationale. My concern is, rather, with a question which is likely to be encountered by social actors whenever they are faced with the need to decide whether a given situation falls under "risk" or "uncertainty". What are the consequences of this decision in terms of the processes of knowledge production and of intervention?

The field of medicine and health raises a number of interesting problems in this respect. On the one hand, many of the situations dealt with in medical practice and public health are amenable to definitions of risk and to preventive or therapeutic intervention based on well-known features of the problem. On the other hand, however, it is common for situations to arise which seem to fall within the "uncertainty" category. Other situations, still, seem to display features of both.[1] How to decide whether a situation should be brought under the category of "risk" or of "uncertainty"? What are the consequences of choosing one or the other? And how to act upon uncertainty? This generates tensions within the field which may be briefly illustrated with the case of lung cancer.

The probability of occurrence of new cases of lung cancer in a population of smokers with a given age and gender distribution can be determined on the basis of the knowledge of the past history of that population and of populations with similar profiles. Other kinds of knowledge such as that arising from laboratory studies of mutations following exposure to substances contained in cigarettes allows the correlation of smoking and risk of lung cancer to be associated with an explanation of the etiology of the disease. This is a common exercise in epidemiology and, in its different versions, a key source of knowledge underlying public health policies towards the prevention of lung cancer and,

[1] For a discussion of these issues in relation to tumour pathology, see Nunes (2002).

more generally, it may be regarded as a model for this kind of interventions when other types of cancer, for instance, are involved.

We should keep in mind, however, that the precise identification of both risks and etiological paths is not always possible for all types of cancer. Some of these are the outcome of heterogeneous processes which intersect and interact in such ways that, even if the features of these processes (or at least some of them) taken separately are known in detail, any attempt to assess the possible consequences of the "unruly complexity" arising from their intersecting and interacting dynamics will be doomed to failure (Taylor, 2001a, b). As a consequence, standard procedures for identifying and assessing risks may be far from adequate to deal with these situations. In fact, as many researchers in the fields of oncology and oncobiology have often stressed, the huge majority of human cancers has its origin in environmental aggressions or in exposures to hazardous entities or substances which are most often outcomes of human activities (cigarette smoke, organic pollutants generated by industrial activities or by the use of fossil fuels, food additives and others). These trigger chains of genetic mutations which lead, in turn, to tissue disorganization, to the proliferation of abnormal cells and to the deregulation of the balance of cell proliferation and programmed cell death (apoptosis), and, finally, to the invasion or migration of these "renegade cells" to different parts of the organism.

The set of diseases subsumed under the label of cancer can thus be defined as the outcome of polygenic dynamics (that is, processes involving several genes), a range of factors acting on different levels or scales of biological organization and multiple intersections of one and the other with environmental processes, social organization, life styles and consumer practices, available medical technologies and access to the latter, timely interventions of health professionals and the existence and effectiveness of adequate environmental and public health policies.

Whereas it would be possible to carry out assessments of risk and developing, for instance, preventive interventions (campaigns against smoking, for instance), these exercises in risk assessment and risk management are partial responses to specific features of a more general "ecology of health problems" which is more properly described using the vocabulary of *uncertainty*. Many of the problems – and, in particular, those with more serious collective impacts – health professionals and health researchers are faced with are of this kind: symptoms are identified, but no etiology has been established; conditions of

exposure to carcinogens or other hazardous agents are difficult to establish; these exposures may lead to a diversity of effects, often spread over time and space, sometimes revealing themselves only in the next generation; long-term effects of exposure to low doses are unknown and no means are available to measure them before symptoms appear; synergies are likely to exist as an outcome of the interaction between different substances, agents or processes; individual susceptibilities may vary due to genetic polymorphisms or to other "host factors" associated with individual, family or group histories… We could go on with this list, but the items mentioned will be enough to illustrate the problem.

These situations certainly do not display features such as a limited number of well-defined variables based on sufficiently detailed information, providing the means to evaluate risks and act to prevent or minimize the effects of adverse events. We are faced, instead, with a variety of heterogeneous and contingent processes whose intersection and "unruly" complexity generate singular configurations. Each specific, situated episode of an endemic, emerging, epidemic or environmentally-related disease and each individual affected by the disease are expressions – ecological or embodied but always the outcome of a history – of that singularity.

The problem of uncertainty in the health domain is not the consequence of insufficient knowledge which could be dealt with through progressive and cumulative advances, allowing for an increasingly greater capacity for risk assessment and preventive action. Uncertainty is, rather, a constitutive feature of a domain which has to deal with two recurrent and inexhaustible sources of uncertainty and of "unruly complexity": eco-social dynamics and the contingent relationship between populations and cases.

Under these conditions, the needs of a collective and situated management of some health problems very easily overwhelm the capacities of existing tools, such as the more classical approaches to disease etiology based on the model of infectious disease and on some version of Koch's postulates, or what some have labelled the "dominant epidemiological approach" (Zavestoski, S. *et al*. 2002). But this problem also arises at another scale in medical practice, since the knowledge of the probability of occurrence of a disease or of a given therapeutic outcome in a given population does not provide knowledge of the specific individuals who will be affected. The latter is precisely the greatest challenge that clinical practice has to face: how to deal with the singularity embodied in specific cases? How to make use of the knowledge generated by public health

and biomedical researchers? To what extent is it possible to decompose that singularity so as to recognize, on the one hand, the commonalities of the various cases of the "same" pathology, and, on the other hand, the sense of the singularity of each case as the emerging outcome of the contingent intersection of heterogeneous procedures framed by a history?

Any approach aimed at tackling simultaneously complexity and singularity will have to draw on the constellation of forms of knowledge which biomedicine and the health sciences have constructed throughout their history. But, if we are to take into account the sources of uncertainty mentioned above, and which are to be found far beyond the conventional objects and territories of the health sciences, we shall have to include other forms of knowledge, both those which deal with eco-social features and those which make it possible to reconstruct the singularity of cases and connect them to broader contexts and populations of cases. This, in fact, points towards one of the original features of clinical practice, the capacity and availability of the practitioner to deal with experience-based knowledge – what the ancient Greeks called, sometimes in a deprecating way, *metis*, practical, cunning reason. This kind of knowledge is local and situated (Scott, 1998). Experience-based knowledge provides an irreplaceable contribution to innovative ways of asking questions, framing problems and shaping answers, as long as it is taken up as part of a reconfiguration of forms of knowledge on health and disease.

This knowledge increasingly appears as *distributed* among different kinds of actors. "Lay" citizens, patients or their families and friends provide a range of informations and experiences on the lived, embodied experience of disease and of caring for the diseased, of symptoms, etiologies, the accuracy of diagnoses and the effectiveness of therapies. They often display unmatched skills in providing knowledge on local settings and circumstances and life stories which shape the singularity of cases. These modes of knowledge are to be included in a configuration of resources for the production of knowledge and for deliberation on forms of intervention which will have to be carefully and rigorously assessed as part of an exercise of "weighing the evidence".

Although these problems are common in dealing with a wide range of, if not most, health problems – we should keep in mind, for instance, the multifactorial characteristics of most diseases or the problems met by most health promotion or prevention programs in articulating constraints and possibilities at different scales (global, regional, national, local, population - or subpopulations - specific) – they are most visible in the cases of endemic

and emerging diseases and of the range of pathologies subsumed under the label of "environmental illness". Complexity and singularity interact in ways which require responses that are met neither by conventional approaches to disease based on the model of infectious disease and on some version of Kochs' postulates, nor by what Zavestoski *et al.* (2002) describe as the dominant epidemiological paradigm (DEP) (see also Nunes, 1998).

A closer look at emerging diseases and environmental illness will clarify some of the limitations of theses approaches and of the approaches to epidemiological surveillance associated with them.

The expression "emerging diseases" is now routinely used to describe transmissible diseases which were thought to have been eradicated in the 20th Century, during the so-called epidemiological transition accompanying socio-economic development. The AIDS pandemic, the (re)emergence of some diseases in areas where they were supposed to have been brought under control or their emergence in areas where they were supposed to be absent (such as different "tropical" diseases), the emergence of hepatitis C as an endemic health problem or the development of the resistance of pathogenic agents to antibiotics have brought serious doubts on the adequacy or sufficiency of established approaches to the understanding and prevention of these problems (Levins *et al.*, 1994).

A parallel development is visible in studies of so-called "environmental illnesses" (Kroll-Smith *et al.*, 2000; Krimsky, 2000; Kroll-Smith and Hughes, 1997; Murphy, 2000). Whereas emergent diseases are usually linked to poverty, deprivation, nutritional deficiencies, absence of sewage systems and reliable sources of drinkable water, and a range of ecological problems associated with land use and urban growth, environmental illness refers to conditions which can be linked to exposures to the products or by-products of industrial activity and "modern" lifestyles, an outcome of what Ulrich Beck (1992) called "manufactured risks" – though, as environmental justice activists have pointed out, poverty and deprivation are often associated with residence in contaminated areas (Hofrichter, 2000).

The very existence of these pathologies is often contested within the world of biomedicine, and it is a quite common response of the latter to reduce them to psychiatric conditions. This is linked to the aforementioned limitations of the model of infectious disease and of the dominant epidemiological paradigm, which meet with unsolvable problems when they have to deal with situations where symptoms are identifiable, but an

etiology is not recognizable. In certain cases, when the range of exposures likely to generate the symptoms is either spread across different spatial units or displays singular configurations when specific individuals are considered (even if there may be some overlap among them), or if their effects are expressed in the next generation, for instance, definitions of spatial units, populations, subpopulations or exposure as they are routinely used in epidemiological studies are inadequate. To this we may add the well-known difficulties, associated with the routine exposure to a myriad of known or potentially harmful substances, of identifying sources of contaminants and their pathways, of disentangling the effects of synergies or interactions, or of encompassing adequate spatial and temporal scales.[2]

In terms of both modes of knowledge and modes of intervention, we are dealing here with situations which fall on a continuum going from risk to uncertainty and from prevention to acting to reduce consequences to precaution. Whereas one can find situations where the risk-prevention paradigm is effective, many situations do not clearly fall under that category, and many others are not clearly definable, since they exhibit features of risk and of uncertainty. It should be noticed, too, that many of these situations may be dealt with in one way or the other, with different consequences.

Both emerging diseases and environmental illness share a number of features which suggest the need to look for alternative approaches, which draw on biomedical and epidemiological approaches, to be sure, but as part of a broader and more complex configuration of tools for producing knowledge and for acting, as they tackle the twin problems of complexity and of singularity.

Two broad kinds of approaches have been suggested to respond to these problems. Although many of the features of these approaches were designed to face the lack of resources or of information in settings such as those of Southern hemisphere countries,

[2] The strengths and limitations of the DEP are recognizable in one of the most important studies ever carried out on the risks associated with living in the neighbourhood of hazardous waste landfills, the EUROHAZCON study, which compared the risk of birth defects (non-chromosomal and chromosomal) in local populations of several European countries (Dolk *et al*., 1998; Vrijheld *et al*., 2002). The careful design and execution of the study allowed the researchers to identify additional risk associated with closeness to the landfill, but apart from calls for more research and for the coordination between environmental vigilance and policy responses, it is difficult to use the information provided by the study to help choose between alternative policy initiatives. A more detailed discussion of this and similar studies and of their implications for the articulation of environmental and health policy initiatives will be included in work in progress coordinated by the author.

they are effective means for producing innovative and more appropriate knowledge and modes of intervention in a variety of contexts, both North and South.[3]

Approaches of the first kind include ecosystem health and human ecology and health. The former treats health and disease as "a collective process and recover[s] the 'place' as an organized space for analysis and intervention, seeking to identify (for specific situations) the relations between health conditions and their cultural, social and environmental determinants, within the ecosystems modified by human labor, through an interdisciplinary focus" (Sabroza and Waltner-Toes, 2001: 5; see also Waltner-Toews, 1995; 2002; Waltner-Toews and Wall, 1997; Nielsen, 2001; VanLeeuwen *et al.*, 1999; Rapport *et al*., 1998). This approach goes beyond health conditions and disease as attributes of biomedical entities, such as populations of micro-organisms or parasites, or as the effects of biological activities associated with exposure to toxic or hazardous substances: "Central to an ecosystem approach rooted in complex system theories, then, is the notion that achieving sustainability requires bringing together a variety of legitimate stakeholders, drawing on a variety of accepted bodies of knowledge, to negotiate a learning path based on a series of conflict resolutions within ecological constraints. Continual learning based on a free flow of information and mutual respect, and investment in democratic local governance, are keys to success" (Waltner-Toews, 2001: 13).[4]

Human ecology and health, in turn, coincides largely with ecosystem health, but its scope is broader, its aims being:

- to elucidate interdisciplinary research methods, emphasizing the interface between global science and local knowledge systems and questioning the dichotomy between global and local knowledge;

- to find new forms for knowledge formation or research strategies, involving a combination of anthropological methods (illness narratives, close reading) and natural and social sciences (macro and micro), public health, and the knowledge of those affected by development interventions; and

[3] For ongoing experiences, see the Network for Ecosystem Sustainability and Health (NESH) website (www.nesh.ca).

[4] The scientific and political issues related to the definition of what a system is, what its boundaries are and how to describe and explain its workings are dealt with in an illuminating way in Levins (1998). A major and innovative contribution to the evaluation and critique of both existing and emerging configurations of knowledge can be found in Santos (2001). A discussion of the full range of its implications for the topics dealt with here is beyond the scope of this paper and will be developed elsewhere.

- to establish a conceptual framework based on this new knowledge formation (Follér, 2001: 117; see also Follér and Hansson, 1996).

Combinations of these approaches with the "sentinel areas", "sentinel events", "sentinel actors" and other procedures associated with vigilance and early warning allows a strategic selection of settings for both research and intervention, as well (Samaja, 1996; Teixeira *et al.*, 2002, Ximenes *et al*., 1999; Van Casteren and Leurquin, 1991; Schlaud and Schawartz, 1998).[5]

A complementary set of approaches draws on the notion of embodied and shared experience associated with a broadening of the notion of ontogeny or, alternatively, of the situated construction over time of biological/social entities, of bodies and identities.[6]

Several strands of work are brought together here, ranging from the constellation of contributions to Developmental Systems Theory and its extensions (Oyama, 2000a; 2000b; Oyama *et al*., 2001; Taylor, 2001a; Bateson and Martin, 2000; Fausto-Sterling, 2000) to recent work at the intersection of the sociology of medicine and the sociology of the environment (Kroll-Smith and Floyd, 1997; Kroll-Smith *et al.*, 2000; Murphy, 2000; Zavestoski *et al.*, 2002), the most recent wave of the social studies of science (Berg and Mol, 1998; Law and Hassard, 1999), and testimonies and reflections by patients, activists and committed scientists and physicians (Steingraber, 1998; Hofrichter, 2000). The articulation of these with approaches of the first type allow for new ways of connecting personal troubles and collective problems, following the spirit of Wright Mills's sociological imagination (1959), shaping new forms of *ecosocial* imagination.[7]

Dialogue among all the producers and carriers of the distributed knowledge and experience of health and disease is privileged in this approach. For health professionals and researchers, this involves a challenge to asymmetrical models of knowledge production

[5] For a detailed discussion of the pragmatics of early warning, vigilance and risk, see Chateauraynaud and Torny (1999). Different forms of citizen and collective action are often crucial for the early detection of environmental and health hazards (Hofrichter, 2000). This is particularly relevant in situations where standard procedures of environmental and epidemiological vigilance do not have the required sensitivity or where the hazards originate in previously unknown sources or follow unexpected pathways.

[6] For a detailed discussion of embodiment based on recent developments in cognitive science, see Lakoff and Johnson (1999). The book is an extensive critique of the main traditions of Western philosophy and of their failure to deal adequately with the embodied character of cognition and of experience.

[7] In his discussion of multiple personality, Hacking (1995) provides valuable tools for what can be described, in foucauldian terms, as an analytics of the contested processes of co-construction and reconstruction of experience and of identity. See also Michel Foucault's later work, especially Foucault 1976 and 2001, and Shakespeare and Erickson, 2001.

and of reduction of actors to "objects". Dialogical and participatory initiatives are needed to avoid wasting valuable experience and information and acting on the basis of narrow and exclusionary concepts of knowledge.[8] Knowledge becomes, in this way, a mutually informed co-construction of knowledge about health, opening the way to inclusive procedures for debating and deliberating on appropriate courses of action. The recognition of the agonistic character of any space populated by heterogeneous actors and heterogeneous experiences and forms of knowledge is a crucial condition for precautionary decision in contexts of uncertainty and of a recognition of the conditions for an adequate, bounded and situation-specific use of available tools for "measured action", including, where and when they are appropriate, more conventional approaches to risk assessment and risk management and the tool-kits of biomedicine and epidemiology (Callon *et al.*, 2001).

[8] On the waste of experience and knowledge associated with the established practices of modern science and technology and its consequences, see Santos (2000).

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