

# CHAPTER ONE

## REFIGURING RISK IN MEDICINE AND HEALTHCARE: CRAFTING WILD NARRATIVES

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#### Abstract

Risk does not exist. It is an invention rather than a reality yet it arguably underpins Western societal structures. Etymologically risk is a relatively recent word and one whose origins appear obscure. In Chinese medicine, its relationship to fear locates its influence in the kidneys, with adrenaline. Its various contemporary uses and meanings suggest a hybrid origin, a becoming that melds European commerce and Arabic belief systems with a sense of looking back upon Classical Graeco-Roman heroic identity, for conceptually it has been re-grounded in traditional and gendered Western practices. Its engendered aspects have led to its particular appearance in male-dominated narratives about bravery and adventures in pursuit of finance, treasures or goals. Possible Arabic origins identify something that is accorded by God rather than chance. In this century, Beck's work on 'Risk Society' associates management of risk with Weber's Western consumer materialism and Protestantism. The concept of risk has therefore become an instrument of economics and political and material social governance and yet, Janus-like, risk also constitutes a medium or process, a threshold locus for re-thinking or trialling - and potentially validating - an emergent individual identity, sometimes successfully, sometimes with horrifying consequences. On the one hand risk, associated with scientific measures, can be 'managed' while chance, serendipity and opportunity are 'wild' options that are not 'managed' but fast acquiring marginal eco-credentials. In Chinese medicine, its relationship to fear locates risk's influence in the kidneys, with adrenaline. It is therefore arguable that mainstream Western society itself operates from the kidney position, from fear of a future intangible. Risk offers a means of transformation, a promise of value and ultimately a mediation of death or failure, but it equally avoids one of the huge realities of life - uncertainty. This paper explores some of the complex cultural and scientific framings of risk that seek to weight the dice, debating its use as purveyor or guarantor of safety in medical contexts.

#### Introduction

Risk and normality have been thought into being as entities that imply a form of collective nominal solidarity for benchmarking and deviation. By implication they relate to measurement. Yet, neither risk nor normality exists in the 'real' world (the material world of everyday life). Both are particularly symbolic of Western ways of thinking, organizing and reforming the world from within particular and self-reinforcing constructions of knowledge. The medical philosopher, Georges Canguilhem (1991) pointed out in the 1930s that the 'normal' and the 'pathological' were not objective scientific descriptions but contaminated by political, technological and economic values.

Risk is something that is inexistent. It is unknown, but has been scientifically and mathematically brought into being as a calculable (knowable) entity that can be employed as a means of ascertaining some sort of certainty in the face of uncertainty. There is an element of mathematical irony here, of a scientific need to capture the ineffable flux and the surplus of the real world. What is common to both risk and normality is that they comprise a method of gauging the inexistent through a system of containment by measuring and approximation, a movement from the outside in, a boundary making. Yet, life is beautifully uncertain and people are individual, so both measures again attempt to capture intangibles as finite, measureable and manageable. This reflects a Western cultural need to manage life, with normality pertaining to diagnosis and treatment of populations, while risk is more fundamentally about the fear of uncertainty (financially, in terms of interventions, or in the face of death). Yet its meaning holds a quality of serendipity, of potential luck. This paper explores concepts of risk and a selection of different arenas in which it is employed. It applies a range of postmodern methods drawn

from deconstruction, discourse analysis, and reflexive modernity within a feminist framework to effect a reworking of risk.

### **Etymology and cultural connections**

Definitions of risk tend to focus on negative aspects such as hazard, danger or loss, especially in financial terms. The more widely accepted etymology of risk used in Western critical thinking is outlined in Ulrich Beck's opening chapter to *Risk Society* (1992). Traditional etymological dictionaries locate risk as a word travelling into English from French, and into French from Italian where the word appears in Southern Italy during the Middle Ages, travelling with the spread of commerce through the French *récif*, *risqué* and *risquer* into English. Deeper roots show a Latin connection with nautical terms for cliffs and reefs signifying dangers, and with a Greek form meaning stone, root or 'projection of firm land'. Homer describes the fig-tree root grasped by Odysseus that saved him from the Charybdis or whirlpool. In its modern sense, 'risk' returns us to the dangers encountered in Classical heroic epic.

This Western socio-cultural genealogy of risk is visible across most academic disciplines, embedding mathematical and behavioural outcome-based probability frameworks associated with Modernity and founded on trading, capitalism, material culture and Protestantism. It is arguably embedded as a linguistic and structural genealogy rather than a topographical lineality. The Renaissance brought an influx of literature focusing on agency, and the development of exploration, trade and travel offering new horizons. Anthony Giddens (1999) associates this period with risk, new ventures and colonizing as opportunism, while this is the period in which Weber locates the origins of material culture as profit-worthy and pious, where Protestantism is linked with Capitalism. Beck and Giddens both describe 'reflexive modernism' as risk culture.

Beck argues for reflexivity as an agent of change in facing environmental and human consequences of science and industrialization as constituent societal drivers. In so doing, he establishes a paradigm or world-view, an ethos and a collective identity for risk that are fundamentally Western and self-facing. Scott Lash and Brian Wynne (1992: 3-4) describe risk as 'an intellectual and political web across which thread many strands of discourse relating to the slow crisis of modernity and the industrial society...[whose] dominant discourses for all they have taken on the trappings of liberal pluralism, remain firmly instrumental and reductionist'.

The pragmatism of a reductionist view is inevitably seductive and an array of cross-disciplinary research evidences this as a particularly Western dialogue with uncertainty, and a methodology for containing, managing and governing through regulatory practices. In *Philosophy of Risk*, Chicken and Posner (1998: 11) offer a mathematical engineering perspective, defining risk as 'measure of the uncertainty about the ultimate consequences of a particular activity'. In the postmodern arena of outdoor and venture activities, risk is defined as '[a] real or apparent danger [whose] uncertain outcome... can be influenced' (Gilbertson et al, 2006). Associated with managing safety, risk is appropriated as a regulatory marketing tool, for example with children's toys. Yet issues around risk involve perceptions and judgements, especially when stakes are high. Learning about taking risks is culturally perceived as a positive aspect of child development (Tovey, 2007). This goes beyond toys – for example, where parental fear of 'stranger danger' has changed the way that children play today and remains the main barrier to children's access to the outdoors, although reported incidents are sparse, where higher risks come from car accidents (Carver et al, 2008).

### **Leadership and language**

Where today dictionary definitions of risk carry negative connotations of danger and harm, in management terms the opposite is true - a substantive body of work associates being 'risk averse' as signalling a lack of leadership associated with self-centred behaviour and organizational failure (Carmeli and Sheaffer, 2009). As a leadership behavioural characteristic, risk taking has been a 20th Century prerequisite for positive leadership behaviour and an effective measure of decision-making behaviour in both individual and organizational management (Sitkin and Pablo, 1992). Risk is portrayed as necessary for success, associated with superhuman behaviour, linked to a robotic, iterative decision-making process and viewed as something that can have beneficial, engineered outcomes.

The heroic language of medicine, where interventions are enacted, as opposed to healthcare (Lupton, 1994), accompanies that of risk in this modality, as medicine succumbs to the lure of success through 'strong' leadership and managerialism. As an aspirational superhuman thinking machine, risk becomes identified with instrumentalism - productivity and usefulness. However, the risk society, as Beck has pointed out with some irony, is one 'increasingly occupied with debating, preventing and managing risks that it itself has produced' (Beck, 2006: 332). Questions about an uncertain etymology

based on a Eurocentric lens reveal that a wider diversity in thinking about the word 'risk' might offer space for creative expansion.

In his detailed polemic on the etymology of the French word *risque*, Laurent Magne (2010) offers a discourse of potential roots that indicate the polyvalent complexity of the word. Etymologically, 'risk' refers as much to human psycho-socio-cultural preoccupations as to its more common meaning as an economic evaluation frequently associated with probability in management and business. Yet the flip side of crisis or danger concealed and revealed by risk strategies presents opportunities and even serendipity, although these are two different things. Magne (2010) excavates these plural readings, locates the signifier (risk) within the concepts of the semantic development of a range of other words (the signified) and from a consciously Eurocentric and Western perspective presents different socio-cultural contexts for risk. He widens his remit to acknowledge this Western view and a lack of readings of an Arabic root in the literature, yet while he refutes Giddens' (1990) and Weber's (modernist projects) in favour of his semiological one, arguably they are compatible.

Magne argues that the contested etymology and obscure origins of the word 'risk' have become so embedded in the modern capitalist project that its ancient origins have become obscured. He specifically deconstructs etymological roots presented by Bernstein (1996) as 'hazardous rock in the sea', to reconsider international commerce via Graeco-Byzantine and Arabic trading routes with Italy as the locus for the development of the idea of risk. He argues for an Arabic etymological origin as a signifier of 'lot', meaning that which Allah provides as a blessing in relation to material and spiritual wealth. In excess, this is to be shared, but it can also be at hand and be had through active participation (whether collected or earned as work). This is, as Magne (2010: 10) points out, is similar to the Ancient Greek world-view of 'lot' or destiny, an aspect of which is wishing to go against the Gods (hubris), a fate punishable by nemesis. Risk is inseparable from a cluster of concepts related to world order and social order located within an ideology of moderation. This has roots in both Arabic and Greek cultures, with notions of prosperity and good business being predestined by a divine origin, demonstrable also in the medieval Christian world.

Magne aligns this with practices and interdictions on interest and money lending. His thesis then refutes the modernist project that locates the appearance of the word 'risk' in the emergence of capitalism in 16th Century Italy, becoming a simple expression of the everyday practicalities for things that may go out of control in business. From a Western viewpoint this is fundamentally problematic as it takes little account of the breadth of cultural changes developing within 14th to 16th Century Italian commerce, particularly in relation to banking, where promissory or provisory notes in exchange for delivery of goods was becoming more frequent and projected business into an uncertain future. Magne highlights that our view of 'risk' is then Eurocentric, a somewhat naïve position in that it does not engage with the complexity of the machinery of Eurocentricity. Critically, Magne's text does not consider the racist politics of othering and Beck's call to consider this.

Multiple meanings and origins are therefore embedded in the word 'risk'. Indeed, current Western understanding of the concept of risk would appear to an extent to fuse these together, in a concept so powerful that it has even travelled back in time to repopulate more ancient situations, bringing together the idea of a 'lot' in life governed by the Gods. It is hard to ignore the fact that the word 'risk', irrespective of its etymology, signifies uncertainty and therefore the future. The concept of 'lot' is melded with aspects of individual heroism and encounters with danger, mediating attributes of personal leadership such as bravery or cowardice with rationalization. This offers a tool to support facing of risk or to justify risk aversion, distancing the danger and offering the illusion that risk can be managed.

Risk, therefore can be contextualised within the move from beliefs in the power of the Gods/God as director of fate to that of the individual having an ability or potential to make his or her own way. It straddles a dynamics of choice and, with the 19th Century advent of institutionalized State powers over the individual, it straddles it again, giving birth to an entire science of how to measure and deal with uncertainty.

However, risk management is also a regulatory governance methodology linked to a deeply embedded politics of self-actualization through reflexivity, specifically of the Western Modernity discussed by Habermas, Giddens and Beck. Risk measurement is therefore designed as a process of mediation, for encounters with frightening things, initially death, but by extension personal (professional and State) failures. It is also a means of quantifying, measuring and assessing things relating to the management of large numbers, complex situations, finances and aspects of governance in the Foucauldian sense of the institutional powers enacting the authority of the State over peoples (Foucault, 1988).

## Health

Peter Dahler-Larsen (2011) argues for the diagnostic abilities of reflexive modernity in ascertaining the problems in contemporary modern society. Out of perceived 'risk' arises historical governance of healthcare for an increasing citizen population in the latter part of the industrial revolution. Doctors are taught how to diagnose and treat within a biological model of what is normal, and a statistical model of what is uncertain.

Management of healthcare transitioned more firmly from the individual to the State during industrialization in the form of hospitals established via the Church and in some instances via Royal dispensation. For the governance of large peoples the corresponding increasing rule of correlations based on mathematical assessments in medicine has offered assurances with regard to welfare in terms of:

- diagnosis (basing diagnosis and professional education on a hierarchy of symptom frequency that of necessity eliminates the infrequent and unusual);
- treatment (what works for most people becoming protocol);
- medicine (an exact science of manufacturing, quantifying and prescribing) and;
- care (rationalized via time management).

In the biomedical paradigm the medium of illness acts to impersonalize an individual's human body for the purpose of diagnosis and treatment. This intervention is subject to risk assessment and management, sometimes but not always shared with the individual. The system is itself, of course, heavily dependent on the good will and vocational professionalism of large numbers of people and the understanding that patients have that this is the case. The management of the system underestimates this trade in 'care' at its peril.

A plethora of threads of networked external and internal consequences across medicine and healthcare form an interwoven risk 'text' and necessitate risk 'assessment' and 'management' of those consequences. The commercial activity of drug manufacture has for some time driven the increasing rule of scientific risk-based research in medicine based on mathematically designed trials that offered both manufacturers and prospective purchasers a 'gold' standard in respect of safety. This meant trading on an assurance that in large populations very few individuals might have adverse reactions, or a low risk correlation. In an era in Western countries where more and more medicines are consumed, there is an ageing population, and an increased rise in obesity, diabetes and autoimmune illness. It has become necessary to individualize and contextualize new ways of working with illness. Managing the risks associated with the chemical interactions of drugs that may take place in the body of a person who is taking a range of different medicines together, and one for which drugs research was unprepared, has become a new focus of the consequences of medical intervention. A rise in more individualized treatment, or patient-centred medicine, includes recognizing patient expertise in their own conditions, part of the newly developing field of personalized medicine (Swan, 2009).

A forerunner of this trend, rebutting traditional scientific and positivist risk methodologies, is the recognition of toxic waste activism. For Lupton (1993) the consequence of lifestyle choices (discussed below under food marketing) is one of two sorts of public health risk discourses, with hazardous societal by-products being the other. Localized disease clusters related to environmental hazards have evidenced non-traditional (lower class, female) lay expertise and established critiques that rebut and highlight the differences between public and scientific perceptions of risk (Brown, 1995:102). Indeed, localised contamination by toxic waste that correlates with cancers and other illnesses in clusters, despite scientific risk evidence, has demonstrated that the model presents a particular perception dangerously far from lived lives and removed from notions of even domestic environmental justice. This is a powerful argument for epidemiology with a social justice focus through the elevation of public health concerns, but it also requires consideration of uncertainty and therefore of risk. The boundary of the inter-relation between public and private spheres is precisely the fertile space in which the Arts and Humanities operate and from where they offer expertise, demonstrating innovative ways of negotiating and engaging in communication.

Another aspect of market-driven medical intervention requiring new forms of risk management is the overuse of antibiotics leading to the rise of antibiotic resistant germs. A rising incidence of autoimmune illnesses with a wide range of contributory factors, including environmental triggers, stress and diet, has led to the developing field of environmental medicine. Further, concerns and issues around food and diet demonstrate similarly problematic market-driven consequences influencing consumer behaviour and health - for example in the changing use of sugar in everyday foods, the demand-driven provision of unseasonal and unripened foods, as well as shelf-life and refrigeration-led

genetic modifications (Nestle, 2002). Linked to this, as an issue of risk and related governance, are management proposals linking obesity, diet and poverty in the UK (Cummins and MacIntyre, 2006). The digestive system - and its risk properties - is placed at the centre of individual and public health. Environmentally, in lay activist terms, the knowledge processes of the 'slow' movement demonstrates an additional and eco-centric view of international and local environmental risk perceptions in relation to food, and diet.

Nowhere does this debate between the individual and the State become more critical than when it concerns life and death, and indeed to whom the life of an individual belongs. This is clear, for example, in the euthanasia debate. It is also clear, from a different perspective, in consideration of risk during medical treatment, with potential consequences of litigation. The burden of responsibility is enacted as a transaction, and while the risk for the professional necessitates a sharing process prior to treatment, in reality it is only the professional and not the individual risk that can be shared, or the theoretical (and emotional) but not the practical. The irony is that the risk is not equal, and that in this evaluation, medical treatment and life are both afforded financial values. While what is a life worth is individual, globally incomparable, and profoundly inequitable, it is externalized, away from an individual. The technologies of modernity afford a dehumanizing cost basis to life, death and the area in between (damage). The role of risk in transactions crossing ethical divides is extremely complex. It is not straightforward in these real-life aspects, nor is it binary, but entangled and messy.

Regulation is a political business. The growth of bureaucracy fits with the project of modernity in the Western world. Bureaucracy is a post-colonial and re-colonizing process that restricts and paralyzes movement. Yet, the reflexive approach is an ancient one, originating in the healthy self-questioning practices of individual dialecticism. As a bureaucratic function, risk-driven management is metaphorically and literally stressful. Propelled by outcomes and facing the future it is driven by fear, again located in the kidneys in East Asian medicine. Adrenally responsive, it is always alert for things to go wrong. It is a watchful Janus-figure of the threshold, with one eye looking to the past and the other to an uncertain future societally programmed with a rapid, but limited, cognitive function. Whatever mathematics and cognitive psychology aim to assert, this is not a neutral figure: regulatory mechanisms aside, it can be creatively reconfigured to be plurally read and mis-read as a metaphor for social change.

### **Refiguring**

The dynamics of risk presented in mainstream social, historical and managerial contexts are overloaded with paternalist, Western governance in Foucauldian and feminist terms. Intrinsically linked to Western Classical heroism and laced with aspects of deadly danger, risk is presented as affordable in the sense that it offers a promise of individual success. This may come to nothing depending on the throw of the dice, or the will of the Gods, a sort of containment of events that sometimes involves a righting of wrongs done to individuals, and might today comprise a natural order of things, as a form of moral discourse. It is interesting that in this particular model personal wit - a kind of street-wise sense relative to the immediate environment coupled with the ability to sense and seize opportunities - is more important than skills of integrity. In this Western representation of the heroic, skills are necessarily gendered male and recognizably human although extreme in scale. The hero's environment is frequently a territory, being difficult, alien or dangerous, feminized as virgin, to be mapped or conquered. Bound up in metaphors of colonialism, this is also the space occupied by societal out-riders: the rogue, adventurer, pirate, financial wizard and potential law-breaker.

Gender-testifying narratives of success are disseminated through narratives that permeate Western culture extending from Ancient Greek and Roman myth into philosophy, psychoanalysis and contemporary films and books (Patterson, 1993). The concept of the individual against the odds extends politically through the heroic to the individual risking all against the state. It is arguable that any notion of a singular heroic is completely misleading as the role creatively lends itself to being viewed as a 'syndrome' of gender-imposed traits of masculinity, even a multiple personality disorder in relation to changing cultural and historical environments and expectations (Nagy, 2013). Yet, this is also one of the faces of leadership. One important general theme and counter theme is that the importance of community is inversely important in relation to the perceived threat to the protagonist. So, ultimately, the promise of risk is that of a re-cognition or re-thinking of the heroic; the creation or forging of individual identity and worth, a measuring against the odds that takes place through the medium of risk. The doctor, too, is archetypal hero as medicine follows the martial metaphors of 'conquering' and 'eradicating' disease.

Ulrick Beck's view of a second modernity is a self-reflexive one that raises issues of trust and credibility in relation to risk and the dominance of the institutions of science and technology (including

medicine) as powerful creators and managers of knowledge about risk. Science and technology in this analogy become corporate bankers trading in a currency of risk in today's 'risk society'.

### **Risk and trust**

If risk originates in a shared understanding of the governance of a Western world-order as an active governance of uncertain futures, whether self-reflexive or not, then it is equally important to highlight the gendered origins implicit in all of these discourses and their deployment across science, engineering, technology and medicine (STEM). STEM fields are traditionally and historically associated with invention and heroism with high status, engendered white, socially self-reproducing stereotypes. They are fields from which women have been until recently excluded and in which both women and minority ethics are persistently under represented with recognizable hermeneutic self-determining and out-moded characteristics (Smeding, 2012; Beede et al, 2011). These are the fields that drive the technologies of positivist risk mechanism as the means of managing or dialoguing with uncertainty.

In any politics of equity, this raises further issues of trust, as risks are both regulated and generated by the practices of the institutions that create them. To benefit from these practices is to accept an internalizing of these risks and their regulation. In other words, risk is a confection that both reveals and hides the dangers it distances and conceals. It is a symptom of what is wrong with modernity, of societal illness. Within this framework, mistrust is compounded by the constraints of modernity around science and public knowledge, as a form of policing that is particularly evident around the borders and intersections between institutions and the public sphere, between research and practice, measured as benefits and losses, physical reactions and individual experiences. Yet, this is also where creativity and new ways of knowing are created. So risk and trust are highly polarized political activities that relate to social roles, and as such they incorporate and embed the politics of their origins.

Carter (1995), in a discussion of HIV/AIDS, points out that neither Beck nor Giddens consider trust and reflexivity in relation to intimacy. Thinking in some detail about dialogues of othering, Carter considers how the construction of identity has a dependency on incomplete conceptualizing of self and other built on ideas of trust rooted in concepts that may fail, such as romantic heteronormative or feminized love as prophylaxis: 'the linear association between risk avoidance and risk awareness is likely to be disrupted by complexities of the relationship between sex and identity' (Carter, 1995: 163).

An ethics of care, such as that grounded in Carol Gilligan's (1982) work, emphasizes the relational nature of research and the emotional aspects of reason. The complex politics of relational positioning shaped by binary, rational logic underpins the pragmatic science of risk assessment outlined above. With woman traditionally othered in the process, Luce Irigaray (1993: 13) outlines her thoughts on what this means:

'Who or what the other is, I never know. But the other who is forever unknowable is the one who differs from me sexually. This feeling of surprise, astonishment, and wonder in the face of the unknowable ought to be returned to its locus: that of sexual difference'.

In consequence, therefore 'jamming the theoretical machinery itself...suspending its pretension of a production of a [univocal] truth and a [univocal] meaning' (Irigaray, 1977, trans 1985: 78), wonder in the face of difference returns us to radical uncertainty – an authentic relational risk.

### **Conclusion**

The historical trajectory of the word 'risk' is, as I have demonstrated, associated with a wide range of social concepts and meanings whose current 'line of flight' may be celebration of difference that informs a critical feminist ethics. Risk might be seen as working at the boundaries with 'found' objects that are creatively reworked. Risk is also risqué, outside of society, without morals, a sort of pornography, a bawdy talk of science, as it were, a form of 'cunt' that is fragmentarily and differently lived and embodied. Face to face with the environmental implications of the way life is lived in the West and as a feminist critical theorist, I echo Haraway's (1998) nervousness in using postmodern critical tools to face the real world - the disassembling and dissembling deconstruction of power within positivist science from a split position that can never experience so-called 'objectivity'. The call for situated knowledges as forms of embodied practice supports constructing 'knowledge of how meanings and bodies are made, not to deny how meanings and bodies get made but in order to build meanings and bodies that have a chance for life' (Haraway, 1998: 580). This presents me with consideration of metaphors, symptoms and translations as ways of unearthing and reworking shared and differentiated movements across those boundaries.

As a herbalist, working with the earth in situ, permaculture offers a responsive mechanism based on ecological sustainability, a responsive ethical relational model where a greater diversity benefits the intervention taking place. Growing plants seems to me more of a responsive miracle than an ‘organic symbiosis’ (Haraway, 1998: 581). It is dependent on external factors that can be mediated but not controlled; qualities of earth, air, sun and water. In an ontology of air, as Irigaray has observed, and on another temporal threshold in a clinical setting, I share breath with an other as I listen, and also with the earth as I breathe.

Risk faces both backwards and forwards in the present. Like Janus (the January after winter) it is a metaphor for a doorway that has the potential to be a portal. Its textual representations are symptomatic of Western social illness that includes a fear of death and loss. Yet the threat of risk, as a powerful organizing force and incentive for particular collective adherence to regulations, enables refiguring or tracing of a different identity. Risk is a symbol of chance or opportunity, of the serendipity for a dialogue with life and death, and with not being able to control the world. It therefore offers a relational gift, a transcendent narrative potential. Moulded and refracted by social processes, from a feminist perspective risk embodies the potential disruption of binary identities and thought processes within Western societal fabric, affording a conversation with chance and the random. The Surrealist Paul Éluard (1929) wrote: ‘the earth is blue like an orange, never a mistake words do not lie’. The text holds relative truth. Rethinking the fragmented temporal multiplicity of risk – with its rhizomatic etymology – encourages creative encounters and ‘wild’ thinking.

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