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Original Citation

Heyman, Bob (2013) Health care through the 'lens of risk': reflections on the recent series of four special issues. *Health, Risk & Society*, 15 (8). pp. 615-623. ISSN 1369-8575

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Health Care through the 'Lens of Risk': Reflections of the four special issues of *Health, Risk & Society*

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Abstract

This editorial reviews the four special issues of *Health, Risk & Society* on *Health Care Through the 'Lens of Risk'* guest-edited by Bob Heyman, Andy Alaszewski and Patrick Brown in 2012-2013 which marked the twentieth anniversary of the publication of the Royal Society *Risk* report in 1992. In these Issues we showed how the objectivist definition of risk in this monograph as '*the probability that a particular adverse event occurs during a stated period of time, or results from a particular challenge*' could be fruitfully reframed from an interpretivist standpoint. From this perspective, events are considered to derive variably from categorisation, adversity from negative valuing, probabilities from uncertain expectations, and stated periods of time from time-framing. In the editorial, I provide an overview of 23 research papers published in the special issues with references to the potential of interpretivist approaches to the social science of risk, and offer reflections on the strengths and limitations of this paradigm.

Introduction

Over the last two years, Andy Alaszewski, Patrick Brown and I have guest-edited a special issue series of *Health, Risk & Society* entitled *Health Care Through the 'Lens of Risk'*, using the 20th anniversary of the Royal Society (1992) *Risk* monograph as the starting point. The four linked issues were organised around the definition of risk in this monograph as '*the probability that a particular adverse event occurs during a stated period of time, or results from a particular challenge*' (p. 2). Each issue challenged the report's attempt to establish the foundations for a science of quantitative risk assessment through an interpretivist reframing of one of the four components which the definition refers to, building on Heyman, Shaw Alaszewski and Titterton's critique of the objectivist approach to risk (2010, pp.20-21).

In terms of this critique, 'events' cannot be identified without categorisation which lumps together selected diverse phenomena into perceived equivalence, differentiating them from 'the rest'. Perceptions that events are 'adverse' entail value judgements. Probabilities derive from a variety of methods for constructing uncertain expectations. Even if they are based on inductive evidence, multiple probabilities of the same event can be reasonably calculated, depending upon the observer's knowledge and choices from available information. Periods of time cannot be '*stated*' unless the observer has framed time in a particular way. (The alternate '*results from a particular challenge*' in the Royal Society definition appears to set an indefinite temporal horizon for risk assessment. It inadvertently precludes the advocated quantification of risks since consequence chains can in principle extend to infinity.) From an interpretivist stance, risks cannot 'exist' independently of observers. In nature, unique individual events merely happen. The construction of risks as

objective entities requires tacit socio-culturally mediated projections of judgements onto events, as in the conversion of negatively valuing into the attribute of adversity.

Critical social scientists, including the contributors to these special issues, seek to unravel such projections. Bog-standard interpretive social science can be used to challenge prevailing forms of risk governmentality which rely on attempted suppression of debates about potentially controversial issues. The contested risk issues explored in this series from interpretive perspectives include the health effects of electromagnetic radiation, normal birthing, older parenting, illicit drug use, alcohol consumption, self-harming, patient non-compliance, the rehabilitation of offenders, child protection, public health, delay in cancer self-referral and being a young person not in education, employment or training (a NEET). As well as contributing to literatures on these topics from risk social science perspectives, the assembling of papers on risk categorisation, valuing, uncertain expecting and time-framing allows common features to be identified across ranges of diverse social contexts, as briefly documented in the next-but-one section.

My fellow guest editors have kindly granted me the last word on the special issue series. The brief comments which follow are organised into three parts: firstly, some remarks about the origins and current significance of the Royal Society *Risk* monograph; secondly, a retrospective overview of the four special issues; and, thirdly, some wider reflectionsⁱ about the strengths and limitations of interpretivist approaches to the social science of health risk. I would like to particularly thank Patrick Brown for unfailing support, sharp critical comments and unearthing promising authors; and Andy Alaszewski for supporting this experiment in his journal which combines a clear but broad focus on the social science of health risk with flexibility in relation to paper length and form.

The Royal Society 1992 Risk monograph 20 years on

Although acknowledging social scientific challenges to the objectification of risk even in the Introduction, the monograph opens on an uncompromisingly quantitative note which may seem dated 20 years later, stating (p. 4) that a '*general concept of risk is the chance, in quantitative terms, of a defined hazard occurring. It thereby combines a probabilistic measure of the occurrence of the primary event(s) with a measure of the consequences of that/those event(s)*'. This starting-point was challenged in a later part of the *Risk* monograph itself. Pidgeon, the lead author of the chapter on risk perception, and Horlick-Jones, an author of the following chapter on risk management were interviewed for this special issue series (Heyman and Brown, 2012; 2013b). In the interviews, they offered detailed insights into the conflicts over risk objectivity which resulted in the report not being endorsed as a Royal Society approved document having collective rather than individual authorship. In his interview, Horlick-Jones tentatively credited Chris Hood, lead author of the second social science chapter, with inventing the epithet '*four chapters good, two chapters bad*', a reference to Orwell's *Animal Farm*, in response to Royal Society unease about the two social science chapters. Horlick-Jones commented that the issue of interpretivism *versus* objectivism not only divides social from natural scientists, but is also found within the social sciences. Pidgeon stated that the report may have become a best-seller because it engaged with this controversy. He noted that it was reappraised by new science policy advisors in the Royal Society four or five years

later as state-of-the art, and provided the impetus for a subsequent large UK government funded *Risk and Human Behaviour* research programme.

Despite its age, the *Risk* monograph remains influential, with a current citation factor of 65 in the two-year period 2011-2012, or 59 if references in our special issues are excluded, and the citations have a global reach. It must be admitted that the main driver for our series was not to celebrate the monograph's 20th anniversary, but to contribute to the subversion of the objectivist assumptions underlying the exceptionally clear definition of risk, quoted above, which was its starting point.

The 'Lens of Risk' special issue series

The first of the four special issues, on the categorisation of health risks, was published in April 2012, and the last, a double issue on risk, health and time appeared in November 2013. The first call for papers went out in 2010 and the project took about double the initially anticipated length of time to complete. A total of 23 substantive research or review papers were published, plus accounts of interviews with 8 significant contributors to risk social science (Nick Pidgeon, Joost Van Loon, Ortwin Renn, Judith Green, Peter Taylor-Gooby, Tom Horlick-Jones, Paul Slovic and Andy Alaszewski)ⁱⁱ and 7 editorials. The combined length of the special issues and annexes is over 600 pages, considerably in excess of most academic books. The special issue series offers a distinctive but little used genre, more flexible than an edited book, and with a publication time-spread which allows the authors of later papers to draw on those already published.

Of the 23 substantive papers published in the series, 16 derived from fieldwork undertaken in the UK, 4 from continental Europe, and 2 from North America. The international contributions were most welcome. The UK predominance among the papers located in rich countries perhaps reflects the strength of the critical risk social science in this country, to which the *Risk* monograph contributed, as well as the propensity for authors to submit to their national journals. Only one paperⁱⁱⁱ, a powerful analysis of the tension between medical and traditional categorisations of malaria/nzoka in rural Tanzania (Desmond, Prost and Wight, 2012) considered risk outside the developed world. This narrowness of remit may result, at least to some extent, from the status of societally organised risk consciousness as a luxury item.

Just two of the 23 substantive papers drew in whole or in part on quantitative methods (Kayali and Iqbal, 2012; Young, King, Harper and Humphreys, 2013), a pattern which reflects the overall preference for qualitative methods in current interpretive social science. But the papers demonstrate the potential for quantifying risk perceptions, as against objectified risks which have been divorced from their observers. This distinction is well-illustrated by the work of Kayali and Iqbal (2012) who dichotomised women's accounts of depression into those which did and did not identify any external triggers, regardless of their 'reasonableness'. For example, one research participant believed that the 9/11 attack on the New York Trade Centre had triggered a depression episode even though she had no personal connections with anyone who had been directly affected. The authors concluded that about half their sample could and could not, identify external triggers, and that identifying a trigger was strongly associated with believing that their depression was not permanent. This

intuitively plausible finding would hold true even if it was not born out by retrospectively observed outcomes.

The structure of the special issue series separated out categorisation, valuing, uncertain expecting and time-framing for analytical purposes. However, these four ingredients of the risk compound are interrelated. For example, lengthening or shortening the temporal horizon within which risked consequences such as cancer recurrence will be considered increases or decreases their observed frequency of occurrence. Authors were invited to foreground the topic under consideration but to relate their analysis to the other three highlighted concerns as appropriate. The assignment of papers to a particular issue could be somewhat arbitrary. One article was hastily reoriented so that it could be published in the time special issue because the writers had missed the earlier deadline for papers on risk categorisation! The same project, investigating the accounts of their actions given by people who self-harm, was drawn on in relation to both the value (Barton-Breck and Heyman, 2012) and time-framing (West, Newton and Barton-Breck, 2013) issues.

Compilation illustrates the range of risk-related topics which the adopted structure encompassed. With respect, firstly, to construction of risked 'events' through socially mediated but largely tacit processes of categorisation, papers were published on: the struggles of self-defined electro-hypersensitivity sufferers to obtain official recognition (De Graff and Bröer, 2012); combined usage of malaria and nzoka as disease categories in rural Africa (Desmond Prost and Wight, 2012); delineating subcategories of depression experientially (Kayali and Iqbal, 2012); how older women understand the nature of a disease, osteoporosis, the existence of which arises from marking an arbitrary cut-off on a continuous measure, bone-density (Skolbekken, Østerlie and Forsmo, 2012); and midwives' understandings about the ever-narrowing status of low-risk, 'normal' pregnancy (Scammell and Alaszewski, 2012). The last paper is of particular interest because it tracks a process of second-order abstraction whereby higher relative risk becomes a clinical entity in itself.

A key theme in these articles is tension between personal and medical categorisations of health issues. It is tempting to compare the struggle for recognition of electro-hypersensitivity depicted by De Graff and Bröer with the efforts of the pharmaceutical industry to establish a taken-for-granted existence, and thereby a lucrative market, for conditions such as child attention/deficit hyperactivity disorder which the public may struggle to differentiate from traditional naughtiness (Clarke, 2011). The immanence of CADD/CADHD is sanctified by the claims of science. This supposed disease has spawned an extensive literature on supposed genetic, neurological and, more rarely, social-interactional causes which leaves its existence as an objective entity unquestioned. In contrast, self-defined electro-hypersensitivity sufferers are readily dismissed as cranks, although De Graff and Bröer observed that the Dutch government was willing to recognise this condition as psychologically real. Whether this type of state indulgence will survive in the economic aftermath of the 2007 financial crash remains to be seen.

In relation, secondly, to the often taken-for-granted negative value judgements through which adversity is projected onto 'event' categories, giving them an aura of intrinsic 'adversity', the published papers covered: recreational heroin and cocaine consumer perspectives on safe and risky usage (Caiata-Zufferey, 2012); the benefits

and costs of non-injurious self-harming (Barton-Breck and Heyman, 2012); the prioritisation of protecting the public *versus* reintegration into the community as viewed by discharged forensic mental health service users (Coffey, 2012); a case study of a woman whose action choice put her recovery from anal cancer at serious risk (Heyman, McGrath, Nastro, Lunniss and Davies, 2012); and the value judgements made by pregnant teenagers about their condition (Hoggart, 2012). One theme runs clearly through this work: that individuals frequently challenge the projected medical and societal value judgements which underlie risk-thinking. These debates are complicated by culturally reinforced fusions which blur distinctions between risk factors and outcomes (Heyman *et al.*, 2010, pp. 45-46). Illicit drug use, being a teenage mother and the like are mostly castigated not in themselves, but because they are viewed as giving rise to greater probabilities of other negatively valued states such as developing physical or mental health problems. Risk factors tend to accumulate negativity in their own right, a value judgement which those who have made themselves susceptible to them may vigorously challenge.

With regard, thirdly, to the construction of uncertain expectations, the published articles were concerned with: the complexities of drawing on probabilistic information derived from screening to inform medical decision-making (Austin, Reventlow, Sandøe and Brodersen, 2013); the underestimated impact of the hindsight effect on retrospective blaming in child protection cases (Kearney, 2013); the unreflectively self-fuelling approach through which the accumulation of file-notes in child protection cases comes to be viewed as itself a risk indicator (Stanley, 2013); the inductive prevention paradox, whereby prophylactic measures erase the inductive evidence which might have informed assessment of their utility, in this case for forensic mental health service-users being considered for discharge from secure accommodation (Heyman, Godin, Reynolds and Davies, 2013); media influences on public perceptions about probabilities of disease outbreaks (Young, *et al.*, 2013); probabilistic reasoning and the difficulty of delimiting the precautionary principle in the pharmaceutical industry (Osimani, 2013); and variations in understandings of probabilistic information received during pregnancy screening for chromosomal anomalies such as Down's syndrome (Burton-Jeangros, Cavalli, Gouilhers and Hammer, 2013). The papers illustrate the many and varied difficulties and paradoxes inherent in the quintessential step in risk-thinking of building expectations about the future from probability quantifications. This process generates apparently precise numbers which conceal more than they reveal.

With respect, fourthly and finally, to risk, health and time, the guest editors had anticipated that this topic would be the trickiest to find material for. However, we ended up with sufficient material for a double special issue. The published papers covered: home drinking in relation to concerns about the present and future (Foster and Heyman, 2013); the decision-making of older women about when to become pregnant (Locke and Budds, 2013); constructions of their futures by patients with advanced cancer (Brown and De Graaf, 2013); the temporal considerations of individuals who self-harm (West, Newton and Barton-Breck, 2013); and accounts of their time management given by patients who develop malignant melanoma (Topping, Nkosana-Nyawata and Heyman, 2013). The original call for papers referred to 'time-framing', drawing attention to the propensity of policy-makers, healthcare professionals and public to set temporal horizons beyond which risk assessment is not considered, as with the convention of assessing five-year survival

for cancer treatments. However, this agenda would have excluded consideration of variations in understandings of temporality within an operational time frame, such as discounting the future at different rates and reappraising timeliness in retrospect. The term 'time-shaping' might have been more appropriate for drawing attention to a set of issues which are seriously neglected in risk social science even though the main purpose of the 'lens of risk' is to attempt to manage what might come to pass.

The strengths and limitations of Interpretivist approaches to risk

The third and final part of this article will outline in editorial declarative style some reflections about the strengths and limitations of interpretive social science approaches to health risks. The hoary age of theoretical frameworks such as symbolic interactionism (Mead, 1934; Blumer, 1969) exposes those of us who continue to use them to the charge of being behind-the-times. However, the ongoing value of applying such well-worn approaches to health and other issues arises from the propensity of members of risk societies to treat risks **as if** they exist materially and independently of observers. In this way, citizens living in risk-oriented cultures project categorisations, values, uncertain expectations and time-frames onto unique occurrences. The differentiation and homogenisation of selected risk factor and outcome categories into reified 'virtual objects' (Van Loon, 2002) is a prerequisite for achieving organised coherence in risk-focussed social spheres such as healthcare. This stricture can be applied equally to clinical understandings of the complex health issues discussed in *Health, Risk & Society* and to service 'tools' such as risk-based hospital management and risk registers. But the treatment of constructed risk objects as substantive material entities must be achieved in the face of the inescapable epistemology of risk which requires observer judgements. Interpretive social science can, in principle at least^{iv}, act as an antithesis, providing ammunition for the many clinicians, service-users and members of the public who challenge prevailing operational over-simplifications.

Objections to this positive spin on the value of critical risk social science can be raised in relation to its intellectual integrity and its relevance to both the situations of developed societies coming to terms with the financial crash of 2007 and the longer-term crisis facing the prevailing global political economy. Adequate analysis of these issues goes well beyond the scope of an editorial or the present writer's competence, but I will sketch out a few ideas. With respect to the validity of qualitative social science in general, it is often pointed out that the accumulation of knowledge depends upon researchers interpreting social actors' meaningful actions and reconstructed accounts, most commonly the latter. Those of us who undertake studies focussed on the experience of health issues have a tendency to turn our attention away from our own role in actively constructing knowledge. This concern can be responded to in a number of ways. One influential analysis (Hall and Callery, 2001) calls for greater reflectivity from researchers who attempt to operate within a quasi-inductive, modified grounded theory framework. More pessimistically, from a relativistic postmodern critique, it can be argued that researchers merely construct or co-construct accounts of accounts which become a phenomenon to be explained by further accounts, *ad infinitum*.

I believe that I and many other practising researchers tend to block out such doubts. This blind-spot, ironically, matches the limitations of operational risk-thinking outlined

above. However, counter-arguments to postmodernist pessimism can be put forward. Firstly, and perhaps lamely, qualitative researchers may feel intuitively that their research does reflect, however imperfectly, the perspectives of their participants independently of themselves. At the least, some of the raw data, admittedly filtered by researcher selection and manufactured through an interactional research process, is displayed for the reader to judge. In contrast, quantitative methodologies conceal such interpretive processes, as in, for instance, the judgements required for content analysis. Good qualitative researchers go to great lengths to see if they can disconfirm their own presuppositions, in part because 'anomalies' add to the richness of the findings, and, for the same reason, look out for unanticipated 'surprises'. Perhaps most importantly, as argued by Green (2009), researchers can challenge a creeping meta-narrative in terms of which researchers become desensitised to alternative framings such as the 'lens of enjoyment' through viewing every issue through the 'lens of risk'. A useful methodological stricture for qualitative risk researchers is to avoid, minimise or delay mentioning 'risk' in their interview topic guides.

Larger external challenges to the prevailing paradigm of qualitative health risk research can be identified with respect to both the current crisis in developed societies and the future of the global political economy. Some governments, most particularly that of the UK, have responded to the financial crash of 2007 by partly dismantling health and welfare systems which are being drastically slimmed down, fragmented and privatised at the same time as wages are being squeezed. It is not easy to disentangle the drivers of pecuniary necessity from that of 'self-hating' government opposition to the state fuelled by the ideology of neoliberalism. A consequence of this transformation is that services which researchers critiqued in happier times for insensitivity simply cease to exist, become so reduced in scope, or become so commercialised that grumbings about their orientation start to seem like niceties. The current paradigm of health care research depends upon the operation of a wider social democratic consensus which, for better or worse, is under severe if not fatal attack.

For example, research into the support needs of UK young carers (Heyman and Heyman, 2013) suggested that services for family members with disabilities needed to be better integrated with those directed at young carers. The fieldwork was carried out by Anna Heyman in the first decade of the present century before the subsequent shrinkage of these services had got underway. Such losses arguably make otiose previous debates about how they might be better fine-tuned. An obvious and justified rejoinder is that cost-effectiveness becomes more important than ever when resources get scarcer, and that micro research into service-user perspectives can contribute towards ensuring that public funding is used as wisely as possible. Nevertheless, as argued by Taylor-Gooby (Heyman and Brown, 2013b), a focus confined solely to tinkering with the details, however important, of service delivery can cause researchers to become blind to bigger paradigm changes in the political economy which are thereby allowed to pass unchallenged. His critique calls not for the abandonment of service-oriented research, but for a complementary strand of risk research which addresses the larger political economy.

Finally, on an even bigger scale, risk social science needs to address the future of the now global socio-economic system. Pessimists, including the present author,

identify a set of mega-risks which feeble international governance, overwhelmed by national self-interest and the power of multinational private companies, is spectacularly failing to address. These risks include human-induced runaway climate change, vital resource depletion, pollution, loss of antibiotic resistance, and unintended consequences of system complexification (Japp and Kusche, 2008) as illustrated by the financial crash. It is possible to visualise a crisis arising from just one of these risks occurring on so large a scale^v that it overwhelms protective systems, as might happen if a solar storm of the intensity expected at least once per century destroys national electricity grids (Odenwald and Green, 2008); or destruction of the social order arising from two or more crises occurring simultaneously, fuelling each other. The work of Beck which first brought him to prominence has been diluted by social scientific debates, appropriate within their limits, about the extent to which the public do frame their lives in terms of risk consciousness (Tulloch and Lupton, 2003). Beck previously envisaged (1992, quoted author's emphasis) that '*in its mere continuity industrial society exists the stage of world history on the tip-toes of normality via the back stairs of side effects*'.

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ⁱ As I am retiring in March 2014, I have thrown academic caution to the wind in the final section.

ⁱⁱ A common feature which emerged from these interviews was accounts of reinvention as a risk social scientist after stumbling into it fairly inadvertently from other areas. For example, Alaszewski became interested in risk through talking to vulnerable adults with learning disabilities living in institutions; and Horlick-Jones' work originated from his role as a policy adviser on disaster planning for the Greater London Council which earned him the press epithet of 'Mr Disaster'. My own interest was triggered in the late 1980s when I heard adults with moderate learning disabilities and their family carers talking in terms which could readily be translated into the language of risk. When I looked for a quick fix on this topic in psychology and sociology texts, I found that it wasn't even mentioned in the indexes at that time. The current generation of younger academics can draw upon a vast, even overblown, published literature and are generating more refined, second-generation theoretical analyses (Zinn, 2008; Brown, 2013).

ⁱⁱⁱ One interesting paper concerned with the prevalence of narratives blaming women for HIV in a developing country marked by substantial gender inequality unfortunately didn't quite make it into print.

^{iv} At the time of writing, in November 2013, many researchers employed by UK universities will have recently participated in the just-completed Research Excellence Framework (REF) quinquennial research evaluation. The 2014 exercise required evidence of non-academic impact. Those who undertake critical research have learnt how difficult it is to demonstrate within this simple, arguably simplistic, framework that their work actually makes a difference.

^v In recent times, the 2011 Fukushima nuclear accident in Japan and the 2013 Hurricane Haiyan in the Philippines with the highest ever recorded wind speed provide examples of mid-scale catastrophes that national and international systems can just about cope with. Others, equally serious, such as the spread of the Sahara receive much less media attention because they unfold more slowly.