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PROBABILITIES AND HEALTH RISKS
A QUALITATIVE APPROACH

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ABSTRACT

Health risks, defined in terms of the probability that an individual will suffer a particular type of adverse health event within a given time period, can be understood as referencing either natural entities or complex patterns of belief which incorporate the observer's values and knowledge, the position adopted in the present paper. The subjectivity inherent in judgements about adversity and time frames can be easily recognised, but social scientists have tended to accept uncritically the objectivity of probability. Most commonly in health risk analysis, the term probability refers to rates established by induction, and so requires the definition of a numerator and denominator. Depending upon their specification, many probabilities may be reasonably postulated for the same event, and individuals may change their risks by deciding to seek or avoid information. These apparent absurdities can be understood if probability is conceptualised as the projection of expectation onto the external world. Probabilities based on induction from observed frequencies provide glimpses of the future at the price of acceptance of the simplifying heuristic that statistics derived from aggregate groups can be validly attributed to individuals within them. The paper illustrates four implications of this conceptualisation of probability with qualitative data from a variety of sources, particularly a' study of genetic counselling for pregnant women in a UK hospital. Firstly, the official selection of a specific probability heuristic reflects organisational constraints and values as well as predictive optimisation. Secondly, professionals and service users must work to maintain the facticity of an established heuristic in the face of alternatives. Thirdly, individuals, both lay and professional, manage probabilistic information in ways which support their strategic objectives. Fourthly, predictively sub-optimum schema, for example the idea of AIDS as a gay plague, may be selected because they match prevailing social value systems.

KEYWORDS

Dogberry: *You are to bid any man stand, in the prince's name.*

Watchman: *How, if 'a will not stand?*

Dogberry: *Why then, take no note of him, but let him go; and presently call the rest of the watch together, and thank God you are rid of a knave.*

Verges: *If he will not stand when he is bidden, he is none of the prince's subjects.*

Dogberry: *True, and they are to meddle with none but the prince's subjects.*

Much Ado About Nothing, Act III, Sc iii.

INTRODUCTION

In the above quotation, Shakespeare illustrates the way in which expectations about a danger can be controlled, and even reduced to nothing, through the adroit management of concepts. The present paper will explore the operation of such processes in the everyday practice of health care. The qualitative data drawn upon has been discussed in more detail elsewhere (Heyman, 1998). Here, we will outline a qualitative approach to probability, and demonstrate its applicability in the analysis of health care transactions. This approach maintains both that the term 'probability' covers a family of meanings which are only loosely related, and that multiple probabilities may be reasonably ascribed to the same event.

The paper will, firstly, locate probability as an element within the complex concept of risk. It will then outline the variable family of meanings of 'probability' which are employed in health risk analysis. Next, we will introduce the idea of multiple probabilities of the same event, our central theme. Probability estimates based on induction from observed frequencies require prior specification of the collectives to be used as numerators and denominators in probability ratios. Choices made about these parameters enable individuals and social groups to achieve the apparently impossible, changing the probability of a person experiencing a future event merely by reconceptualising it.

We will consider two ramifications of multiple probabilities. Firstly, individuals and organisations may define the numerators and denominators in risk ratios so as to support prior strategic aims, using

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differentiation and generalisation to demonstrate that a risk is unacceptably high, or too small to justify preventative efforts. Secondly, the delimitation of risk numerators and denominators may be influenced by cultural stereotypes which thereby affect the probabilities of adverse events attributed to members of such groups. Since health risks are subject to recursive processes, involving preventative/deregulatory responses to their assessment and psychosomatic effects, the selection of probabilities involves more than just an accounting device.

PROBABILITY AND RISK

Cursory analysis of news contents will show that risk occupies a central place in contemporary culture, and provides a tool used to foresee and control the future in disparate spheres such as weather forecasting, business management, environmental protection, crime control, transport and health care. In the *'risk society'* (Beck, 1992), individuals' personal identities, and their relationships to wider social structures, have become bound up with their attitudes towards the multiplicity of personal, economic, political and ecological risks about which their culture encourages concern.

Because the term is used so pervasively, risks are often viewed as natural phenomena. However, the concept of risk is built up through the integration of a set of lower order ideas, themselves complex. The Royal Society (1992, p2) has defined risk as *'the probability that a particular adverse event occurs during a stated time period, or results from a particular challenge'*. This definition contains four analytical elements, shown in Table 1, below. Each can be treated as a property of the world (left column) or of our understanding of the world (right column). We will ignore the sub-clause in the Royal Society definition about resulting from *'a particular challenge'* which covers cases in which the probability calculation within a risk appraisal is not time-delimited.

TABLE 1

TWO VIEWS OF RISK ELEMENTS

Risk elements viewed as objective properties	Risk elements viewed as perceptual qualities
Events	Categories
Adversity	Value
Stated time period	Time frames
Probability	Expectation

Events/Categories

Viewed as natural phenomena, event classes such as diseases appear to stand out objectively from the background of non-events of a particular type, just as species may be differentiated by their inability to inter-breed (Anderson, 1991). Although nature is sometimes inherently clumpy, descriptions of events inescapably entail decisions to differentiate a class of phenomena from the background, accentuating both their similarity and distinctiveness. Many objects of health analysis, including schizophrenia (Kringlen, 1994), child abuse (Jackson *et al.*, 1995) and Down's syndrome (Rapp, 1988), encompass quantitatively and qualitatively different phenomena.

The size of the numerator in a probability ratio for a condition depends upon the way it is defined and operationalised to distinguish 'cases' from 'non-cases'. For example, if only more serious cases were counted as examples of child abuse, then its incidence, and thus its probability, would be reduced, even though the condition of children would not have changed. However, the tendency of many health events to involve qualitative shifts, e.g. death, tumour growth, combines with the propensity of the medical profession to develop social conventions about the definition of disease entities to limit disagreement about the categorisation of probability numerators. For this reason, qualitative analysis of the ways in which professionals and lay people actually induce probabilities most often turns up disagreements concerning the denominator.

Adversity/Value

The concept of adversity (see Table 1) projects negative value judgements onto constituted event classes. Negativity ultimately rests in the eye of the beholder (Rescher, 1983) although the common human condition guarantees that diseases and disabilities will generally be regarded as adversities. Value conflicts arise most usually when efforts to prevent one negativity cause another, as in disputes between those who seek to minimise genetic abnormalities and those concerned with the rights of the unborn child. Individuals arrive at their own personal balance between the costs and benefits of risky activities, e.g. healthy foods versus snacks (Backett, Davison and Mullen, 1994), or autonomy versus safety for vulnerable people (Heyman and Huckle, 1993).

However, the personal tragedy theory of disability has been strongly criticised (Oliver, 1990). For example, some deaf people argue that they should be considered as a linguistic minority rather than as imperfectly hearing people (Lane, 1995). Laing's (1968) idea of schizophrenia as a learning experience, although unfashionable today, has not been totally abandoned by people diagnosed as schizophrenic. In general, the externalisation of adversity onto health events entails value judgements, usually implicit, and sometimes contested, about desirable normality.

Stated Time Periods/Time Frames

The Royal Society notion of a *'stated time period'* in the left column of Table 1 is reconstituted as a variable time frame on the right. Since infirmity and death can only be delayed, not prevented, the negativity of an adverse health event depends upon when it occurs. Quantitative risk analysts often discount time at the inflation-adjusted rate of return in financial markets (Viscusi, 1992). Such technically driven procedures are based on arbitrary value judgements, and provide a simplistic substitute for exploration of the variable, socially situated, calculations which individuals make about their own futures. For example, an impoverished, unemployed young person living on a sink estate might begin to inject drugs with a dirty needle because the future seems bleak, whilst a mother on the

same estate might desperately seek to survive serious illness out of concern for the welfare of her children.

<u>Probability/Expectation</u>

The objectivity of probability appears to stand out from the subjectivity of categories, values and time frames. Rescher (1983) supports this view when he distinguishes the 'facts' of probability from values judgements about negativity. We do not wish to adopt a relativistic analysis of probability, arguing only that **many** probabilities, but not that **any** probability, of an event may be reasonably proposed in the light of inductive evidence. The selection of a plausible probability may be affected by value considerations.

Social scientists who have eloquently criticised naïve realism in risk analysis with respect to event constitution, value judgements and imposition of time frames, have adopted deferential attitudes to the epistemology of probability. Hansson (1993, p. 20) asserts that *'the reliability of risk analysis depends on the absence of systematic differences between objective probabilities and experts' estimates of those probabilities'*. Lupton (1993, p. 425) maintains that *'In its original usage, "risk" is neutral, referring to probability, or the mathematical likelihood of an event occurring'*. However, as will be argued below, probabilities depend upon the observer's knowledge, and so can never be objective or neutral in the sense of excluding the observer.

Social scientists may have deferred to the objectivity of probability because (like the present authors) they can only understand the mathematics of probability theory and statistics at a rudimentary level. However, this vast edifice rests on the assumption of randomness. Only to the extent that complex events in the real world take an approximately random form, can such mathematical tools can be usefully applied. Shafer (1990, p. 119) argues that *'random, like probability is a loaded word'*, and prefers the *'possibly less divisive older'* term *'expectation'*. The gap between the abstract mathematics of chance and the pseudo-randomness of the real world needs to be explored.

A QUALITATIVE APPROACH TO PROBABILITY

Suppes (1994, p. 18), from a Bayesian perspective, defines a qualitative theory of subjective probability as one which accepts that the term can be applied in various ways and that *'two reasonable men in approximately the same circumstances can hold differing beliefs about the probability of an event unobserved'*. The analysis of multiple probabilities, in the next section, will show why beliefs rather than frequencies should be considered the proper object of probabilistic analysis. Expectations can be based on evidence in a variety of ways. These include:

1. Expectations based on good inductive knowledge of accepted frequencies.

2, Expectations based on limited inductive knowledge of accepted frequencies.

3. Expectations where frequencies are questioned.

4. Expectations derived from theoretical models.

5. Expectations based on composite considerations.

Where an inductive knowledge base for expectation has been established, individuals may seek and obtain as much knowledge as possible about their possible future (type 1), may try but fail to obtain relevant information (type 2), or may choose not to know, for instance by deciding not to undertake a diagnostic test (type 2). Type 3 refers to adverse event classes for which frequency patterns are questioned, as with new health problems, those which have not been researched and those about which measurement problems have been raised. Such second order uncertainty about the reliability of an inductively based expectation will be considered further below.

Expectations may also be derived from theories, themselves more or less justified by inductive and deductive evidence (type 4). Some people are convinced, for example, that the world will end on

December 31st 1999. This example can be used to draw a distinction between subjective and reasonable expectation. The former refers only to a belief about the future, whilst the latter is grounded in evidence from statistically valid induction or deduction from empirically well-supported theory. We wish to argue only that many expectations may be reasonably induced from similar data, not that all should be ascribed equal truth value. Because of the complexity of health phenomena, direct induction usually plays a major role in prediction, for example in the assessment of disease incidence, and expectations cannot be based solely on deductions from theory.

Finally, in much medical practice, expectations are based on consideration of combinations of evidence (type 5). Faced with a unique case, presenting a constellation of symptoms, social background and biography, doctors will weigh up the likelihood of alternative diagnoses. Since each case requires the observer to confront a unique pattern of evidence, conclusions cannot be derived from known frequencies in a straightforward way. This form of reasoning can be compared to that employed by a jury considering the probability of a defendant's guilt, given a particular array of evidence, one of the original concerns of classical probability theory.

Konold (1989) concluded from a qualitative study that individuals accounting for events, for example a conjunction of adversities, reasoned in one of two distinct ways. They either thought probabilistically (e.g. that coincidences do happen), or developed a detailed explanation (for example speculating about causal links between the conjoined events). Individuals may attempt to predict the future by considering a specific case in all its complexity, or make analysis more manageable by simplifying, drawing on the probability heuristic, as will be argued below. This choice is readily available only in cultures which emphasise probabilistic reasoning and the concept of the average, a relatively recent phenomenon associated with the development of science in modern Western societies (Hacking, 1975).

Expectations Based on Well-Established Relative Frequencies

Risk analysis requires the integration of lower level elements, event categories, values, time frames and expectations which can each be understood in different ways. Induction from established frequencies provides only one way of approaching expectations. This small corner of risk analysis plays a particularly important role in the health domain because health risks mostly occur frequently in large populations. They may be induced from empirical observation of past frequencies in a way which is precluded for rare events such as catastrophic nuclear accidents. Induction from observed frequencies entails acts of classification, often implicit and unreflective, of numerators and denominators. These may be used, as already noted, to compute an overall rate of a health problem within a given population, or to calculate rates in sub-groups which can then be compared. Their employment as a guide to the future entails the standard inductive assumption, sometimes questionable, that the future will repeat the past. Induction rests on particularly shaky ground where the expectations in question involve human action, for example the probability that young people will use illicit substances, or that patients will comply with medical advice. Even though the use of aggregate 'social facts' frees the investigator from having to predict the behaviour of individuals, inductive expectations are still vulnerable to the effects of cultural shifts.

Health Probabilities and Games of Chance

Classical Western probability analysis draws heavily on games of chance, with the spinning of a fair coin providing an archetypical exemplar. However, we may imagine a skilled conjurer who, within severe limits of speed and number of rotations, can control a tossed coin so that he can always predict which way up it will land. 'Randomness' only applies above the level of complexity at which the conjurer cannot monitor or control the coin's behaviour. But complexity, like value and time-frames, cannot be projected solely onto events. The level of complexity at which coin tosses become 'random' depends upon the skill of the spinner or observer. Thompson (1986) imagines a robot capable of calculating the outcome of tosses with perfect accurately. Necessity and chance can be seen as *'a dialectical couple'* (Winkler, 1990, p. 128). Such observer-relative complexity thresholds can be easily found in health risk analysis. For example, genetic probes now enable the transmission of many

genetic problems to be predicted with total accuracy, where, previously, only probabilistic estimates, based on family history, could be given.

The outcome of an individual coin toss is entirely determined and predictable, providing that it is not affected by quantum effects. Individually, it has a probability of either 1 or 0 of landing on heads, as becomes clear to any observer after the event. To suggest otherwise implies that it can exist in a superposition of two states, an assumption unnecessary outside the bizarre world of quantum mechanics. The leading protagonist of the frequentist approach to probability, von Mises (1957, cited by Weatherford, 1982, p. 167), insisted that the concept of probability could only be properly applied to collectives, for example a long series of coin tosses, not to individual events. Bayesians, in contrast, argue that a probability such as 0.5 refers to the strength of an observer's belief, justified as far as possible by inductive evidence, that the coin will land on heads.

Both frequentists and Bayesians, thus, deny that randomness can be validly considered a property of individual events. However, Reichenbach (1949, cited by Weatherford, 1982, p. 162), another prominent frequentist, maintained that, for pragmatic purposes, collective probabilities could be applied to individuals using an *'eliptic mode of speech'* in which probability acquired a *'fictitious meaning'*. In more modern terms, the use of probabilities to predict individual futures has heuristic value. For example, a woman weighing up the risk of miscarrying a healthy baby as a result of amniocentesis against the risk of it being born with genetic abnormalities needs to estimate her personal probability of the latter outcome as best she can. She is interested in her own personal future, not the collective risk for women of her age. The inherent limits of inductive probabilities as a guide to individual futures are articulated in the following quotation, from a woman facing surgical treatment for gynaecological cancer, whose consultant had attempted to use probabilistic information to reassure her that her prognosis was excellent.

Patient: *No, I cannot see it positively. You see, I keep thinking that I'll be in the 7% who don't make it.*

Interviewer: *So, has it not helped, knowing that your results are good news?*

Patient: *But, ehm, that's just it. I have no guarantee that I won't be in the 7%. There I go again. I can't stop thinking about that number 7, and that I will end up on that side of the equation. Someone has to. How do I know it won't be me? No, it isn't helpful. It hasn't stopped me worrying. At the moment, I'm really worried about that 7%.*

The heuristic application of collective frequencies to individuals can be defended providing that their crudity is recognised. Moreover, as will be argued below, similar problems arise in the specification of collectives which, except in the limiting case of perfect prediction, can only be provisionally defined in relation to a given stock of knowledge.

The complexity which, in modern Western cultures, we understand as randomness, drawing on games of chance, provides an over-simplified metaphor in two respects, affecting the numerator and the denominator in probability ratios. The numerator, in games of chance, falls into naturally discrete categories. The physical structure of coins, for example, virtually precludes their coming to rest on their edge (and, drawing on the same logic as Shakespeare in *Much Ado About Nothing*, we can rule out this outcome as null). Health problems, however, do not necessarily have discrete natural boundaries, e.g. in the case of schizophrenia or child abuse, as argued above.

In relation to the denominator, the focus for the rest of this paper, coin tosses and other games of chance provide a misleadingly simple example of complexity. Although, in such cases, probabilistic predictions can be based on induction from long-run frequencies, these predictions cannot be made more powerful by differentiating the denominator. Beyond the complexity threshold for a given observer, as discussed above, heads will occur equally frequently for high and low, fast and slow, or perpendicular and angled tosses, or for any combination of these characteristics. Rates of health problems, in contrast, will usually depend upon the way in which the denominator is specified, and its segmentation can be undertaken in an indefinite number of ways, as the following straightforward example will show. Given an observed, long-run, death rate in a population of 1.5%, a naïve observer, ignorant of mortality statistics, might argue that members of this population face a probability of dying over the next year of 0.015. This prediction requires the assumption inherent in all induction, that the

past provides a guide to the future, for example that the population will not be suddenly struck by a new plague. More seriously, it is undifferentiated. If the population is sub-divided, using known mortality indicators such as age, sex, socio-economic status and lifestyle, varying mortality rates will be identified inductively for each cell in the resulting multi-dimensional contingency table.

We might find that one individual, an elderly, poor, overweight, male smoker, now faces a probability of dying in the next year of 0.25, whilst another's risk is reduced to .001. This epidemiologically mundane example illustrates that the same person can have many different probabilities of experiencing a future contingency, depending upon the classification scheme adopted. The illusory impossibility of this outcome arises from the tendency in modern, risk-oriented cultures to treat probability as an objective state of individuals. We are inclined to believe that an individual carries around a unique probability of a future occurrence in the same way as we imagine that a coin, once launched on its trajectory, occupies a superposition of heads and tails. This way of thinking can be corrected by thinking about probabilities, in a frequentist way, as a property of collectives, or by regarding them as inductively based statements of expectation, the position adopted in the present paper.

Von Mises dealt with the problem of alternative collectives by requiring that a proper collective cannot be partitioned into sub-classes with differing rates of occurrence of the outcome in question (Weatherford, 1982, p. 166). However, this requirement precludes the predictive use of collectives in health and virtually any other field of enquiry in which outcomes are associated with complex, interacting and partly unknown antecedents. We can never exclude the possibility that further variables, or combinations of variables, with predictive power will be discovered, requiring current collectives to be divided still further until perfect prediction is achieved. Even in the case of coin tosses, the apparent homogeneity of the collective does not stand up to close analysis. A hyper-sensitive robot, capable of anticipating the outcome of coin tosses with some degree of accuracy, could classify them in terms of initial conditions as more likely to yield heads or tails. Judgement of the indivisibility of a collective with respect to the rate at which an outcome occurs depends upon the state of knowledge which, in the case of medicine, changes rapidly, as already noted.

Our analysis raises the question of whether, and, if so, how a 'correct' way of differentiating the denominator in inductive probability calculations can be identified. The predictive power of a classification scheme depends upon its ability to differentiate sub-populations with higher and lower future rates of a phenomenon. At one theoretical limit, future cases and non-cases might be perfectly predicted. 'Chance' would have been eliminated, and the health problem in question would no longer trouble risk managers. At the other theoretical limit, a differentiation criterion might provide zero predictive power, for example if expectation about a person's fate was based on palmistry. Consideration of these extreme cases shows both that any probabilistic classification encodes, at best, imperfect, and therefore tentative, knowledge; and that empirical evidence allows some forms of differentiation to be preferenced over others. Neither absolutism nor relativism can be sustained. In between, a variety of classification schemes will 'work' predictively, and will generate statistically significant relationships. The scene is set for asking how social actors define the denominator in inductive probability estimates.

The Facticity of Inductive Probability Estimates

The use of inductive probabilities to guide expectation requires adoption of a simplifying heuristic which entails acceptance of the ecological fallacy. Individuals are classified into categories, and are assumed to possess their aggregate properties. The observed rate of an adverse event within a defined collective is projected onto the individuals within it, so that each is placed, for heuristic purposes, in a superposition of states.

The attribution of objective facticity to probability estimates can be seen in our data concerning the ways in which doctors explained the risk of having a baby with Down's syndrome to pregnant women (Henriksen and Heyman, 1998). Unless amniocentesis, which carries a risk of miscarriage, is performed, the baby's genetic status can, at present, only be determined probabilistically. Known risk indicators for Down's syndrome include family history, maternal and paternal age (Mikkelsen *et al.*, 1995), maternal exposure to abdominal x-rays (Rose, 1994), conception in the winter months (Puri and Singh, 1995) and positive serum test results (Cuckle *et al.*, 1987). To complicate matters further, a woman's risk of delivering a live baby with a genetic abnormality reduces significantly during the course of her pregnancy, and approximately halves in the case of trisomy 21, the cause of Down's syndrome, due to a greater rate of spontaneous miscarriage of fetuses with genetic abnormailities (Nicolaides and Campbell, 1996).

In practice, many maternity hospitals, including the site for our research, only consider family history, a rare indicator, maternal age and the results of serum screening, if carried out, in order to target 'high risk' cases. Although maternal age and serum screening provide the most powerful indicators, the other variables mentioned could greatly increase predictive accuracy. According to the authors cited above, a history of maternal abdominal x-rays and conception in the winter months each approximately double the incidence of Down's syndrome, raising the question of why such factors are not used to improve predictive accuracy. Part of the answer is to be found in organisational values, constraints and simplification. Use of a history of maternal abdominal x-rays as a Down's syndrome

indicator raises the spectre of iatrogenic disease, off the agenda in most epidemiological risk research (Skolbekken, 1995). Serum tests are rationed in many UK hospitals because of their cost. Offering tests only to older women allows the majority to be excluded, whilst, for example, use of season of conception as a criterion for testing would greatly increase the number of women who would have to be included. Finally, and most importantly, the use of even simple screening criteria such as maternal age gives rise to organisational complexities which can work against staff efforts to counsel women as well as possible. The busy maternity hospital site for our research had not developed an official policy concerning the maternal age above which serum screening should be offered. Consultants and registrars developed their own idiosyncratic age cut-offs for screening, ranging from 32 to 37 years of age, but did not apply even their own criteria consistently. For instance, one consultant acknowledged that he might forget to offer screening if an older woman looked youthful, or if the phone rang during the genetic counselling session. Such inconsistencies may have resulted, in part, from cultural time-lags, as doctors trained to deal with individual cases attempt to manage late modern health systems geared to targeting risk factors in populations (Castel, 1991). Inconsistencies in the application of screening criteria generated considerable concern among women who noticed them. Since use of a single, simple screening indicator raised so many complex organisational issues, it can be concluded that the employment of multiple criteria within an large organisation would have caused unmanageable complications.

Expectations based on induction from observed frequencies require the specification of collectives. Individuals may be attributed multiple probabilities of the same event, depending upon how populations are sub-divided. Once organisationally fixed, the probabilities derived from such specifications can acquire facticity and be projected onto individuals, as illustrated by the following quotation from tape-recordings of doctors giving genetic counselling at the hospital site for our research.

If you took a large number of women who are 33 having a baby, it [probability of Down's syndrome] *would be 1 in 570. So, if 570 women aged 33 had a baby, one of them, by chance, would have a baby with Down's syndrome.*

However, doctors also took account of the results of serum screening, if undertaken, thus undermining the facticity of maternal age-related probabilities. Cuckle *et al.* (1987) offer a two-dimensional table showing the estimated probability of a baby being born with Down's syndrome as a function of maternal age and 16 different levels of serum alpha-fetoprotein (AFP). For example, a woman aged 35 would, according to this table, face a probability of this event ranging from 1:120 to 1:1800, depending upon her AFP level. One doctor, in our research, distinguished between general (age-related) and personal (test-derived) risk.

> *When you are 40 it's* [probability of Down's syndrome] *1 in 100 alright, so the risk really goes up to around 1% when you are in your later, sort of 30's, maybe 40's. Now, that's for all women, so what I can't tell you at the moment* [until a serum test is carried out] *is what your individual risk is.*

The idea of *'individual risk'*, in the latter part of the quotation, undermined the notion of what risk *'really'* is in the first part, and provides a clear example of the useful *'fiction'* discussed by Reichenbach (1949). Risk estimates which combine maternal age and levels of AFP provide a more differentiated and accurate means of predicting collective rates, but many other risk estimates could be given, depending upon the indicators considered.

Both doctors and pregnant women differed in the degree of facticity which they attributed to probability estimates. The two women quoted below treated maternal age-related risks as objective phenomena:

> *It* [genetic counselling] *made me more aware of the actual risk. She compared from 32 to 36, you know, ... and that made me take more notice.*

> *Well, actually, I found it quite encouraging because I have a 1 in 311 chance, which means that 310 people had to walk through that door before I would end up with a Down's syndrome child.*

The second quotation illustrates a common misunderstanding which stretches the facticity of expectations based on aggregates still further. Inductive probabilities describe irregular sequences of events which occur at regular rates over the long run. The quotation implies a regular sequence, belief in which offers a false sense of security.

Some women were strongly affected by graphical representations of maternal age-related risk which they were shown during genetic counselling. This iconic form carries an aura of objectivity in science-based cultures, whilst backgrounding the assumptions on which a graph is based.

> *What brought it home to me was when the doctor got this graph out. It had ages 30, 31, and you saw the ages going up, and the risks heightening.*

The next quotation shows how a probability estimate which had been fully aggregated at the local level, and so uncoupled from maternal age, could be used to establish the reality of Down's syndrome.

He said that 4,200 or 4,500 babies were born each year at Sunderland, and, out of them, only five of them have Down's syndrome, you know, so he was quite blunt about it.

This undifferentiated estimate provided yet another way of inducing expectations and gave the woman a probability of only .001 of having a baby with Down's syndrome. The consultant who gave the information had intended to provide reassurance, but a subsequent interview with the recipient showed that she found its facticity shocking.

Other women expressed more sceptical views about the statistics which they were expected to trust.

> To me they are just facts and figures. It could mean anything. Who is to say that those figures are right?

Although we have focused on the age-related risk of Down's syndrome, a similar analysis could be made of the risk of miscarriage associated with amniocentesis. Women considering this test, and the professionals who advise them, have to weigh up two quantitatively and qualitatively distinct probabilities, of losing a healthy baby as a result of investigating its genetic status against giving birth to a child with genetic abnormalities.

The probability of a miscarriage could be estimated on the basis of induction from global statistics, as stated by one doctor in genetic counselling:

> The risk of having an amniocentesis test causing a miscarriage, just by the fact of having the test, is probably 1 in 100 to 1 in 200. So, it's balancing the chances of actually having a baby with problems against the risk of causing the loss of pregnancy which might be perfectly normal, and everybody has to make their own choice.

Alternatively, this global probability could be differentiated, generating a completely different picture of the future, as in the next quotation from another genetic counselling session.

> **Doctor:** If you went to amniocentesis direct or indirectly through the blood test, the risk of losing your baby is said to be 1 in 200. So, a little bit more risk of losing a baby

Patient: *Yes*

Doctor: *By the statistics, our local risk is probably a hell of a lot less than that. None of us, as far as we know, have lost a baby, related to the test.*

As well as quoting a substantially lower global risk than the first doctor, without an indication of second order uncertainty, (1:200 against 1:100-1:200) , the second doctor differentiates the more favourable local from the less favourable general statistic. By implication, the below average rate of miscarriage caused by amniocentesis in his own hospital must have been counter-balanced by higher rates elsewhere. Such differences in representation of expectations about the same outcome might be expected to affect women's decision-making considerably. However, doctors mostly used probabilistic information, as far as we could tell, to support the decision which a woman was already leaning towards, rather than to persuade.

Expectations Where Relative Frequencies Have Not Been Firmly Established

When new diseases emerge, detailed epidemiological research has not been carried out, or its reliability is questioned, inductive probability estimates cannot be confidently used to guide expectation. For example, historical data could not be drawn upon in the early days of the AIDS epidemic, or, currently, in the UK, with respect to new variant CJD. In such circumstances, inductively established incidences of hopefully similar diseases may be extrapolated to the new condition, as when the low rate of transmission of Scrapie in sheep to CJD in humans was used to reassure the public about the safety of British beef. Such extrapolations can never be relied upon because a small change in the structure of the disease vector can exert a disproportionate, non-linear effect on its rate of transmission.

Doubts about induction based on observed frequencies can be dealt with through the postulation of second order probabilities (uncertainty about a probability), but the usefulness of such concepts has been questioned. Lehner (1996) has argued persuasively that frequentists, but not Bayesians, can make use of the concept. If probability is understood as the long-run rate at which an event occurs,

then more or less confidence may be placed in inductive estimates, depending upon the reliability of the data collected. But if, as argued in the present paper, probability should be conceptualised as degree of uncertainty, referencing beliefs rather than events, then the notion of uncertainty about uncertainty makes little sense.

A person's expectation that an event will occur can be expressed as a value between 0 and 1, representing complete certainty, respectively, that an event will not or will happen. On this view, total ignorance of the future could be described by a probability of .5 (Teigen, 1988). Since, for example, new variant CJD can have an incubation period of over 20 years, and cannot currently be diagnosed in its early stages, it might be argued that individuals who ate possibly infected meat face a 50% chance of developing the disease. Each person might or might not have been infected, and we have no sound inductive grounds for preferencing one of these possibilities over the other. Such statistics clearly need to be distinguished, within the family of meanings of probability, from those induced from long-run observed frequencies. For this reason, Lehner (1996) prefers to represent second order probability by an interval range, e.g. [0,1], which would indicate, in this case, an underlying continuous value anywhere between impossibility and certainty. The range of the upper and lower bounds would express the degree of second order uncertainty (Walley, 1991). For example, the eventual number of cases of CJD resulting from the UK BSE epidemic in the 1980s might range from the low hundreds to several million. However, individuals managing their own health futures may not handle total uncertainty in this complex way. One of our respondents (Henriksen and Heyman, 1998) initially reasoned that she faced a .5 probability of a miscarriage from amniocentesis because this adverse event might or might not occur.

> *I had, like, understood that it was, like, 50-50 chance* [miscarriage resulting from amniocentesis]. *I think I should have been really hard pushed to make a decision then. But when I saw it was 1 in 200, I thought, "Oh well, go for it"* [amniocentesis].

Genetic counselling had caused her to reassess the probability of amniocentesis causing miscarriage, and this reappraisal had converted a dilemma into an easy decision.

Unexpected adverse events, for example the birth of babies with Down's syndrome to younger mothers (assuming that they see this event as negative) create management problems because the predictive schema which makes an event unexpected directs preventative attention away from them. These difficulties arise directly and inescapably from the approximate, heuristic status of probabilities. Unexpected events can be understood in two distinct ways: as consequences of inherent randomness (Davison *et al.*, 1992); or as evidence of the inadequacy of the predictive schema which led to their categorisation as unlikely to occur. The next quotation, from a caring professional, illustrates the management problems associated with perceived unpredictability in the treacherous sphere of human action.

> *The two people I've got, one of them, there's trigger points, you can actually see the signs of him building up. And you know that there's going to be an outburst, for want of a better expression, you know, well, towards you.* **The other person shows no signs at all.** *There's no trigger points, nothing, and she can just become very very violent towards you for no reason at all.* (Day centre worker for people with learning difficulties, quoted in Heyman *et al.* (1998). Present authors' emphasis.)

The failure of a routine predictive schema can tear a rent in the *'substratum of trust'* (Giddens, 1991, p. 129) on which a person's existential security is based, exposing them to a sense of underlying chaos.

> *A young lady was admitted who was having a miscarriage. Her husband accompanied her, and they were upset because it was their first baby. The husband seemed to me to be very protective and concerned. During the doctor's examination, the lady's father arrived and asked to see his daughter, but her husband made it quite clear that he did not want to see his father-in-law. When the husband saw him talking to the staff nurse in the corridor, he became very angry, swearing at his wife and threatening to do all sorts to the father ...* **It frightened me because I have never seen someone change so quickly** *from being caring and gentle*

to being aggressive and violent. (Student nurse, quoted in Russell and Smith (1998). Present authors' emphasis.)

Since the surprising quality of an unexpected event arises from its lack of correspondence with expectation, it may, alternatively, be dealt with by abandoning or rejecting the heuristic which gave rise to it, as illustrated by the following interview data from our pregnancy research.

I think, sometimes, you look on your past experience. I mean, just about every Down's baby I [older midwife expecting baby] *have looked after, her mum has been under 30.*

This quotation could be dismissed as confusing absolute frequency with rate, since most Down's syndrome babies will be born to younger women simply because of the relative scarcity of older mothers. The respondent uses the availability heuristic (Tversky and Kahneman, 1973), grounding a belief about the underlying probability of an adverse event on personal experience of a small number of cases. However, her challenge to the heuristic linking Down's syndrome to maternal age had some justification in the predictive anomalies which she could cite. By rejecting this heuristic, she could avoid the gloomy trajectory associated with being designated as 'high risk' because of her age.

DIFFERENTIATION AND GENERALISATION

Since expectations based on induction from observed frequencies depend upon the denominator in the probability equation, individuals can influence their own probabilities (expectations) by changing its scope. One powerful means of exercising such control involves managing knowledge. For example, women who are made aware of 'their' maternal age-related risk of having a baby with Down's syndrome must decide whether to accept a test. A woman offered testing is therefore asked to choose between leaving 'her' probability at the aggregate level established by induction for her age group, and taking a test which will either increase or lower it, placing herself in a sub-category with a lower or higher rate of the disorder. She cannot know in advance whether her danger will be

increased or decreased, but can decide whether to find out. One respondent in our research managed to partially articulate this issue.

> *I didn't want to be placed in a position of having to decide about a termination* [as a result of testing]*, because I knew I wouldn't want one. But I thought, "Once you know for a fact that you have a Down's syndrome child, would that change you?"*

By refusing testing, she generalised her probability over the maternal age group, refusing to risk placing herself in a sub-category with a higher incidence of Down's syndrome. In contrast, other women who had ruled out termination in any circumstances decided to accept a serum test because they anticipated a negative, reassuring outcome. In effect, they took a gamble, justified by the relative infrequency of positive results, that the test would place them in the lower risk group.

The woman quoted below, who was receiving Taxol chemotherapy for gynaecological cancer, withheld information about side-effects, tingling and numbness in her fingers and toes, from her doctors because she did not want her treatment to be affected.

> *They* [doctors] *did not need to know. It's nothing to worry about. I mean, what is the most important thing? I'd rather have a few numb fingers than get the cancer back. There was no way I was going to have my dose reduced ... If my dose was reduced, what would that do to my chance of being cured? Reduce them!*

As long as she avoided seeking further information, this patient could classify her symptoms as trivial. However, if she had disclosed them to medical staff, she would have been told that they indicated the presence of peripheral neuropathy, a known serious side-effect of Taxol, requiring reduced drug dosage in future treatment.

It should not be supposed that only lay people use differentiation and generalisation to manage probabilities, as can be seen in the case of Jaymee Bowen, a young girl who died of leukemia in

1996, much admired for her bravery in the face of extreme adversity. Jaymee was refused a second round of NHS treatment on the grounds that she had only a 2% chance of survival which did not justify the extra suffering entailed. Critics suspected that the health authority was mainly concerned about the cost of further intervention, around £60,000. Funding for private treatment was subsequently donated, and the doctor who took over her case sought to discover whether she belonged to a sub-class of leukemia cases with a better chance of survival. Following this investigation, he put her chance of survival at 30%, justifying further treatment which, unfortunately, failed.

Observers might feel that in this, and in many other cases, expert insiders draw upon spuriously accurate statistics in order to give scientific legitimation to pragmatic decisions. Assuming, for the sake of argument, the validity of the statistics quoted, they illustrate the professional use of differentiation and generalisation for pragmatic ends. Thus, an overall aggregate survival rate of 2% within a category of leukemia sufferers may co-exist with a much higher rate among a sub-category which, mathematically, must be balanced by a lower survival rate among the remainder. By deciding whether to seek more information, individuals can choose either to accept an aggregate or to disaggregate it into groups with higher and lower expectations of an adverse event.

SOCIAL CATEGORISATION IN PROBABILITY ESTIMATES

The final main step in our argument relates probabilities to social stereotype. Probability analysis is concerned with expectations about the future rather than with causal explanation. Where expectations are grounded in induction from observed frequencies, many predictive equations will work well enough, even if some can be shown to generate superior forecasts. None will offer freedom from error until the limiting case of totally accurate prediction is reached, and probability analysis can be abandoned. In these unclear epistemological conditions, categorisation may be influenced by social attitudes, as illustrated by the following two examples.

Categorisation, particularly in the early stages, of the Western HIV epidemic as a 'gay plague' has been criticised as both homophobic and epidemiologically unsound (Schiller *et al.*, 1994). Male homosexuality stands as a crude proxy for certain forms of sexual behaviour, e.g. unprotected anal sex with multiple partners, associated with the probability of infection. Sexual orientation does not in itself pose any risks. Gay men in a monogamous relationship with an uninfected partner face no risk of sexual transmission of the disease. The risk factor identified, male homosexuality, became a cultural icon in which emotion and imagery were blended with epidemiological half-truth (Kingham, 1998). Ironically, some groups of gay activists are now promoting themselves as 'high risk' in order to attract resources during the present 'indifference' (Weeks, 1991) phase of the epidemic. Use of male homosexuality as a proxy for high risk sexual behaviour has some pragmatic justification in that it allows at least partial targeting of a group in which high risk behaviour is more concentrated, through the gay community.

Bowler (1993) discusses the linked beliefs of some midwives, observed in one maternity hospital, that Asian women enjoy easier births and tolerate pain less well than other groups. As with male homosexuality in relation to HIV, ethnicity provides a proxy indicator for another variable, parity, which predicts ease of labour, since, at the time of the study, Asian women, in the hospital cachement area, on average, had larger families.

Homophobia and implicit racism should not be defended. In each case, use of an associated social category as a proxy for a more directly related indicator reduces predictive power and generates systematic errors, for example the expectation that Asian women will enjoy quick and easy first deliveries, but will show poor pain tolerance. However, the simplification seen in these examples does not differ in principle from that found in any case of inductive inference from observed frequencies. Individuals are put into categories and aggregate properties of the category are attributed to its members. All probabilistic reasoning of this form entails simplification, and therefore generates systematic errors, but also offers some degree of purchase on the future. The rough and ready character of inductively based expectations allows for many possible ways of grouping data which generate predictions that can be supported by evidence. Mesmerised by statistical significance, or

other indicators of prognostic power, researchers and practitioner may overlook the values and prejudices which led them to model the future in one way rather than another.

DISCUSSION

This paper has offered a qualitative approach to probabilities which has been applied particularly to processes of induction from observed frequencies. We have not considered categories, values or time frames (see Table 1), which must be integrated with probabilities in the interpretation of risks, as their subjectivity is widely recognised. Probabilities, because they can be expressed in a precise numerical form between the zero of impossibility and the one of certainty, added, multiplied and subjected to statistical analysis, are often treated with deference in science-based cultures. In such cultures, those who possess political or socio-economic power use quantification as a means of social control. Complex multi-dimensional strategic objectives which raise dilemmas and value questions are expressed in terms of single numerical indicators. For example, gross national product is widely used to measure societal well-being. In the UK, measures derived from external examination results are employed to assess the success of schools.

Such proxy indicators provide policy makers with convenient tools with which to manage complex problems, since they can simply act in ways designed to maximise the chosen indicator. To the extent that an indicator captures a strategic objective, such policies will confer social benefits. But quantification entails simplification and, in consequence, systematic distortion. An economy which invests large sums in correcting industrial pollution may register a greater GNP than one which does not pollute in the first place. Schools in the UK may improve their performance in league tables by ignoring children who will not score, expelling difficult pupils, or neglecting subjects like music which do not count. Because of their unavoidable imperfections, quantitative indicators and the political decisions which follow from them, become sources of intense conflict between rulers and ruled.

Where proxy indicators are recognised as heuristics, simplifying devices which provide crude but possibly useful summaries of complex realities, these disputes may be resolved through political

debate. For example, indicators may be refined, or exceptions recognised. However, those who rely on such indicators, typically people with social power, may be tempted to confuse a proxy with the complexity which it summarises, treating the pictures it generates as 'reality'. Such naïve realism heads off potential disruption of social systems organised around quantitative indicators, legitimises established social power, and makes complex problems appear more manageable. Our criticism is directed solely at the externalisation of probabilities as descriptions of events in the world rather than summaries of knowledge limitations, not at the use of induction from collectives to inform expectation and practical decision-making.

Probabilities of adverse health events mostly encode partial inductive knowledge. If individuals are grouped according to multiple socio-demographic, lifestyle and genetic criteria, then the observed rates of various health problems in sub-categories will consistently differ. Such data can then be used to target preventative efforts. But inductively based probabilities rest on an act of simplification, requiring the assumption that individuals within a collective specified by an observer carry with them its aggregate properties. Once established as social facts, probabilities change the futures which they were designed to predict through recursive processes (Adams, 1995; Heyman and Henriksen, 1998).

The facticity of the schema which generate inductive probabilities can be subverted by reframing them as reasonable expectations, and pointing out that an individual's probability of experiencing an adverse event depends upon how the collectives which serve as the numerator and denominator in probability rations are defined. Qualitative analysis of probabilities provides a middle way between the relativism of social constructionism and naïve realism. Some schema will yield more predictive power than others. For this reason, the collectives underpinning inductive probabilities cannot be dismissed as mere social constructions (once numerators and denominators have been defined and valued within a time-frame). But an ultimately 'correct' schema cannot be identified except in the special, non-probabilistic, case of perfect prediction, and many alternatives will work well enough. Decisions about the specification of collectives for inductive probability estimates are influenced, usually implicitly, by pragmatic concerns, organisational considerations and social stereotypes.

This paper has offered a theoretical analysis based on a qualitative approach to probability which can complement quantitative approaches. The latter rely upon simplifying heuristics whilst the former are concerned with the assumptions on which such simplification is based. Our analysis can be used to suggest some practical recommendations for further consideration, briefly outlined below:

1. In a risk-oriented culture, health professionals need to learn about the epistemology of risk as well as its epidemiology.

2. Health professionals who communicate about risk need to understand the perspectives of those whom they advise, and to appreciate the influence of personal values, orientation towards the future and culture upon any risk appraisal, lay or scientific.

3. Given the complexity involved in an apparently simple task, health care providers need to develop standard policies, continually reviewed, for describing probabilities, and the uncertainties which they encode, a step already taken by the hospital site for our maternity research. Where appropriate, national and international guidelines should be developed.

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