Commentary: The prevention paradox in lay epidemiology—Rose revisited

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"It has long been a commonplace observation in the discipline of social anthropology that cultural systems of explanation or accountability [for the occurrence of a misfortune] need to address two distinct issues. In the first place the general kind of misfortune: how and why does it happen? In the second place, the site and time of particular misfortune require explanation: how and why did it happen to this person at this time? ... In our own society, where the development of science has shaped so many other cultural institutions, it is sometimes overlooked that this pair of explanations is still required. This is so because it is a central pillar of the Western scientific tradition that the two explanatory systems are unified." 1(p.4)

Rose's seminal paper2 contrasting the consequences of a focus on sick individuals with that on sick populations, stresses the importance of distinguishing between two kinds of aetiological questions, and in so doing demonstrates immediate parallels with the model of anthropological enquiry presented above. In Rose's terms, within the province of predicting and explaining the occurrence of illness, one aetiological question seeks to establish the causes of cases (i.e. the occurrence of a specific disease in a specific individual at a specific time); and the second is concerned with the causes of incidence. Rose opens his paper by drawing attention to the question which he has "often encouraged" medical students to consider when teaching them epidemiology: ‘Why did this patient get this disease at this time?’ This he describes as an ‘excellent starting-point’ given their ‘natural concern for the problems of the individual’.

We would argue that this is also the starting point for the lay epidemiologist and that the concerns of the clinician and the (nascent) epidemiologist have much in common with the lay epidemiologist. Our use of ‘lay epidemiology’ follows Davison et al who describe this as ‘a scheme in which individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and in the public arena’3 (expanded below). This is in contrast to the notion of ‘popular epidemiology’, as framed by Brown,4 which represents public participation in ‘traditional’ (or formal) epidemiology, often through lay advocacy to highlight hitherto ignored environmental hazards or risks such as toxic waste (see also5).

Rose then asserts that an ‘integral part of good doctoring’ is to ask ‘Why did this happen, and could it have been prevented?’6(p.32) The questions drawn out by Davison et al. in relation to anthropology and Rose in relation to the practice of medicine and the teaching of epidemiology illustrate the centrality of the prevention paradox to lay epidemiology.

What is the prevention paradox?

Just as the determinants of disease may differ depending on whether the focus is on the individual or at population level, so too, Rose argues, do the consequences for preventive strategies. Rose contrasts the advantages and disadvantages of the ‘high risk’ and ‘population’ strategies. The ‘high risk’ strategy, he argues, seeks to ‘achieve something like a truncation of the risk distribution’ and has some ‘clear and important advantages’. These centre on the premise that: ‘The intervention makes sense because that individual already has a problem which that particular measure may possibly ameliorate ... The “high risk” strategy produces interventions that are appropriate to the particular individuals advised to take them’.(p.35) This, Rose suggests, raises ‘subject’ and physician motivation, is cost-effective and has a favourable ‘benefit-risk ratio’. However, he also identifies disadvantages. In addition to the difficulties and costs associated with identifying ‘high risk’ individuals (through screening), such interventions are ‘palliative and temporary’:

"The potential for this approach is limited—both for the individual and for the population ... [in part because] our power to predict future disease is usually very weak. Most individuals with risk factors will remain well, at least for some years; contrariwise, unexpected illness may happen to someone who has just received an “all clear” report from a screening examination. ... Often the best predictor of future major disease is the presence of existing minor disease... However, even if screening includes ... tests for early disease, our experience ... still points to a very weak ability to predict the future of any particular individual’.(pp.36–37)

The ‘population strategy’, by contrast, seeks ‘to control the determinants of incidence, to lower the mean level of risk factors, to shift the whole distribution of exposure in a favourable direction. ... In its modern form it is attempting ... to alter some of society’s norms of behaviour’.7(p.37) Amongst its advantages, Rose describes this strategy as ‘radical’, ‘behaviourally appropriate’ and having ‘large potential for populations’. However, Rose identifies a number of ‘weighty drawbacks’, and prominent amongst these is the ‘prevention paradox’:

"[the population strategy] offers only a small benefit to each individual, since most of them were going to be all right anyway, at least for many years. This leads to the prevention paradox: “A preventive measure which brings much benefit to the population [yet] offers little to each participating

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individual” … and thus there is poor motivation for the subject. … In mass prevention each individual has usually only a small expectation of benefit, and this small benefit can easily be outweighed by a small risk’. (p.38)

Rose extrapolates from Framingham study data to suggest that if all men up to age 55 reduced their cholesterol level by 10%, one in 50 could expect to avoid a heart attack on average yet ‘49 out of 50 would eat differently every day for 40 years and perhaps get nothing from it’. (p.1850)

Here we discuss the consequences of the lack of explicit emphasis in much health promotion aimed at preventing coronary heart disease (CHD) of the existence and implications of these two approaches to prevention, and the impact this has had on notions of coronary risk in ‘lay’ epidemiology. We outline the arguments of Davison et al., who drew attention to the importance of the prevention paradox in lay epidemiology, and discuss ways in which we might expect ‘lay’ and ‘professional’ epidemiology to converge and diverge.

Lay epidemiology, ‘coronary candidacy’ and the prevention paradox

Davison, Frankel and Davey Smith have described public perceptions of health risks as ‘the outcome of a process termed “lay epidemiology”’.

‘This refers to a scheme in which individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and in the public arena, as well as from formal and informal evidence arising from other sources, such as television and magazines’. (p.428)

Clearly this includes scientific presentations of risk, including that incorporated into health promotion. Davison et al’s characterization of lay epidemiology derives from qualitative research in South Wales on lay understandings of the causes of CHD. Coronary disease provides a rich seam for the study of lay epidemiology. First, it is a frequent and prominent occurrence in our society (accounting for about a quarter of all deaths and deaths from other sources, such as television and magazines). (p.428)

These figures are frequently invoked. As one respondent in a study in the west of Scotland said:

I mean you get some people who have a dreadful lifestyle but who are very healthy (laughs) and live for years. … Others seem to be doing all the right things and still things go wrong, you know that (laughs). I don’t suppose there’s a hard and fast rule.

Thus, in the assignation of candidacy status, much rests on the personal characteristics (and lifestyle) of individuals. This is unsurprising, perhaps, given Rose’s observation that ‘most non-infectious diseases are still of largely unknown cause… We know quite a lot about the personal characteristics of individuals who are susceptible to them; but for a remarkably large number of our major non-infectious diseases we still do not know the determinants of the incidence rate’. (p.34)

These gaps in knowledge about the determinants of coronary disease were not a prominent feature of health education in the 1980s and 1990s. Instead, the emphasis was on ‘a partial presentation of the epidemiological evidence’ featuring ‘simple message[s] concerning individual risk factors’ via large-scale programmes of primary prevention, in which modification of lifestyle was equated more with the avoidance of disease than the lowering of risk. Little emphasis was given to Rose’s observation that ‘the painful truth is that [even] for … an individual
[with low levels of coronary risk factors] in a Western population the commonest cause of death—by far—is coronary heart disease! Everyone, in fact, is a high-risk individual for this uniquely mass disease.\(^2\)(p.37) Such observations mean that inevitably there will be many anomalous occurrences of CHD which violate the candidacy system and necessitate some recourse to other mechanisms.

Unexplained variation in the incidence of heart disease does not go unrecognized by the lay epidemiologist. Violations to the candidacy system are ‘readily incorporated into the explanatory model as a whole by the simple recognition that candidacy only indicates increased risk while death from heart attack remains famed for its caprice’.\(^1\)(p.14) As Davison \textit{et al.} argue, ‘the observation that “it never seems to happen to the people you expect it to happen to” becomes integrated as a central part of the system itself’.\(^1\)(p.15) Thus notions of ‘randomness’ and ‘fate’ are often invoked, as exemplified here:

For every one fit … you think, there’s another bloke going about smoking and beer belly out to here and living on for ever and ever and seeming to have no adverse effects anyone can see, what’s going on? But that of course, is kind of the Russian Roulette aspect of life, I suppose … (later) … There’s always one that slips through the net that proves you to be wrong yet again, that proves everybody’s theories out of the window!\(^8\)

Thus, the failure of health promotion to more openly discuss ‘the paradoxical nature of population strategies in the general public’\(^1\) and acknowledge Rose’s concerns about the prevention paradox inevitably places undue emphasis on the failure of current scientific theory to explain the ‘anomalous deaths’ and ‘unwarranted survivals’. Davison \textit{et al.} conclude that, ‘It is ironic that such evidently fatalistic cultural concepts should be given more rather than less explanatory power by the activities of modern health education, whose stated goals lie in the opposite direction’.\(^1\)(p.16) Scepticism about the worth of behavioural change has become widespread, and ‘in some respects echoes the doubts of many epidemiologists about the quality of the scientific evidence concerning the nature of risk factors and the benefits to individuals of changed behaviour’.\(^3\)(p.430)

\textbf{Lay and professional epidemiology; ne’er the twain shall part?}

The similarities between lay epidemiology and its professional counterpart are prominent in Davison \textit{et al.}’s analysis of lay epidemiology. This is partly in response to a prevailing view informing public health policy in Britain in the 1980s, that lack of behavioural change must be attributable to lack of knowledge or irrationality. It is also part of a move away from the opposition between patients’ ‘beliefs’ about illness and doctors’ knowledge.\(^16\) Davison \textit{et al.} allied ‘ideas held by the general public regarding coronary heart disease … with the concerns of the epidemiologist’;\(^1\)(p.428) described ‘popular belief systems’ as ‘closer in spirit to the questioning traditions of epidemiology than to the certainties of health education’;\(^3\)(p.428) and observed that ‘the scientific medical fields of symptomatology, nosology, aetiology and epidemiology have identifiable counterparts in the thoughts and activities of people outside the formal medical community’.\(^1\)(p.6) Indeed, Davison \textit{et al.} argued that people’s presentations of their understandings of coronary risk demonstrate the:

‘interpenetration of medical and popular discourse … [questioning] the traditional distinction between professional and lay notions … The non-professional majority are habitual users of the medical idiom when illness is under discussion, and the professional minority remain members of the wider society, sharing the common framework of cultural and moral norms’.\(^9\)(p.329)

The general population’s perception, they concluded, ‘is considerably more sophisticated than is generally appreciated by health educators’.\(^3\)(p.430) Our data support this view, as illustrated by this respondent’s recognition that those who violate the rules of coronary candidacy are exceptions.

You’ll get somebody, who in spite of everything, can remain healthy, but maybe they’re the lucky ones, it’s like Uncle Willie smoked to a 100 and drank … but there are 10 Uncle Willies that never made it, so you know, there’s a lot of different things going on there.\(^8\)

However, whilst we agree that an emphasis on the shared rationale of lay and expert epidemiology is appropriate, it is important that the rationale for differences between the two systems is also considered. Whilst lay epidemiology is centrally concerned with the prevention paradox, as illustrated above, there are other features of Rose’s critique that we would argue are less well understood by the lay epidemiologist, or at least do not feature prominently in lay accounts of the aetiology of heart disease. For example, we did not find any parallels in our research to Rose’s important observations that a lack of heterogeneity in exposure obscures causation, and that ‘a large number of people at a small risk may give rise to more cases of disease than the small number who are at high risk’.\(^2\)(p.37)

In the remainder of the paper, though, we concentrate on the contrast between lay and professional epidemiologists in the meaning of cases.

Rose highlights the fact that ‘The determinants of incidence are not necessarily the same as the causes of cases’.\(^2\)(p.34) We would argue that the causes of individual cases (why this person and why now?) take greater precedence for the lay epidemiologist. The predominant focus on individual cases, differences in the meaning of incident cases, the level and depth of knowledge about potential aetiological factors for a specific case, and the degree of tolerance of ‘unexplained variation’ lead to differences in perspective for the lay and professional epidemiologist.

In many ways the lay epidemiologist, the clinician and the professional epidemiologist undertake remarkably similar exercises in striving to explain the patterning of (usually adverse) events. However, the focus within public health can rest on the majority, i.e. the denominator, whereas for the lay epidemiologist the focus is more often on constituents of the numerator, the particular individual occurrences of premature illness or death which affect their lives and require explanation. We would agree that the construction of notions of candidacy and other understandings of risk in lay epidemiology draw on a wide range of sources (e.g. colleagues, acquaintances, sports people,
politic...make assumptions about health beliefs, attitudes and practice.23–27 Politicians, iconic figures, the stars and characters of soap operas17 as suggested by Davison et al. However, we could contend that events within the family are particularly salient in deconstructing candidacy. Thus, if a family member is an ‘unwarranted survivor’ or more particularly an ‘anomalous death’ this has particular power in undermining the acceptance of well-established epidemiological facts about ‘risk factors’ for major disease. As Gifford has pointed out, there is ‘a fundamental gap which exists between a person’s experience of a given reality and science’s explanation of that same reality’.18 In our culture, family deaths are often our only close experience of death. Each such death is not just an event, adding weight to our observations, or an additional case to increase the numerator or tighten confidence limits around an estimated risk. For the lay epidemiologist each such death is likely to be one of a few defining points in their understandings of risk, and in the collective biographies of friends and family, and thus has the potential to be transforming rather than confirmatory in understandings of risk.

Popay et al. cite criticisms of existing health social science research and epidemiology for its ‘failure to allow for the likely complexity of explanations … [T]he risk factor approach … remains supreme and, to a large extent, continues its quest to isolate risk factors. … This atomistic approach disconnects individuals from their social context, and destroys the structure of the social network within which they are embedded’.19(pp.627–628) In arguing that social science research should pay greater attention to the complexities of lay knowledge, they privilege an analysis of ‘lay knowledge’ as rooted in the places that people spend their lives. Whilst people are attentive to illness and death in wider society, for most, we would argue, it is the family which offers a unique laboratory for the generation of more complex lay epidemiological theories. These are grounded in people’s collected and repeated observations of the experiences of their nearest and dearest. In general, family life offers more opportunities to observe and evaluate intimate experiences of illness and death (and their presumed antecedents) in substantially more detail than is possible for the professional epidemiologist, or for the lay epidemiologist constructing more general theories about candidacy on the basis of observation of more distant, or even fictional (e.g. soap opera), instances. Often the family is the only place where we can observe ‘private’ rather than ‘public’ accounts of displays of the way people live their lives20 extending back over a lifetime. An interest in lifestyle influences on health is prominent within both lay and professional epidemiology. However, observations of the links between a lifetime of experiences and subsequent health events (including mortality) within the family offer the lay epidemiologist potential for more complex theorizing based on extensive and detailed knowledge about factors or experiences which could increase risk, or be potential confounders. These are not confined to events or exposures identified as risk factors a priori (as is the case in formal epidemiology), although retrospective recall is, of course, subject to selective memory and an element of ‘narrative reconstruction’21 in the light of subsequent events.

Whilst observations of life and death in the public domain are powerful because they are based on larger numbers of observations of relationships of more objective ‘facts’ in more simplistic detail, they rest on poorer knowledge of potential confounders and mediating variables. For many years the emphasis within formal epidemiology was on prospective cohort studies (often cited as the ‘gold-standard’ in epidemiological research) and on maximizing sample size to enhance the accuracy of estimation of relative risks; smaller but more detailed studies were devalued. However, more recently some epidemiologists have argued that greater detail on major exposures and potential confounders collected from fewer subjects may provide more accurate risk estimates than larger studies with less accurate measurements.22 The more nuanced observations of close family members thus show some parallels with such longitudinal epidemiological studies, although in such circumstances the ‘lay epidemiologist’ is closer to a tradition of qualitative research than to much of formal epidemiology, even verging towards the role of lay anthropologist as participant observer in the lives of those whose deaths or other health-related misfortunes they strive to explain. The emphasis is not on isolating risk factors, but on contextualizing, qualifying or even rejecting previously accepted risk factors or aetiological theories in the face of contrary personal experience.

Finally, whilst both the professional and the lay epidemiologist accept that understandings of causality are imperfect, the ease with which the ‘inexplicable’ can be tolerated may also differ. Gifford notes that ‘one cannot assume that epidemiologic and clinical notions of risk can be easily translated into lay notions of risk’;18(p.231) Whilst for the professional epidemiologist the refining of aetiology over the course of a decade or two may constitute scientific progress, the need to explain an apparently ‘inexplicable’ death or event in a close family member is much more immediate and compelling.

In conclusion, we would argue that there are many parallels between lay and professional epidemiology, and that the ‘prevention paradox’ is a key site of disquiet within both. However, the response of many population health initiatives has been to emphasize relatively simple messages about risk. Yet within lay epidemiology the differences in the impact and predictability of risk factors at a population and individual level are widely understood; most people have notions about what renders a person a ‘candidate’ for a specific disease (incorporating ‘expert’ epidemiological understandings of risk at the population level) whilst simultaneously understanding that life, health and death defy prediction at an individual level. The failure to acknowledge the prevention paradox more directly in health education material thus can lead, at best, to greater mistrust amongst the general public of the messages contained, and at worst to their outright rejection.1,13 Health education material which builds on a more open acknowledgement of lay knowledge and the sophistication of lay theories about risk at an individual and population level may achieve greater success, since evidence suggests that advice on behavioural change is more effective when based on a clearer understanding of cultural norms informing health beliefs, attitudes and practice.23–27

Prior et al. have noted how ‘the words “knowledge” and “expertise” have come to be freely associated with the lay public as much as with professionals. … This switch of emphasis is appropriate, it is claimed, because lay knowledge is as important as scientific knowledge for an understanding of disease and illness, and consequently deserving of parity of esteem’.16 Whilst some epidemiologists may struggle to accept a notion of complete parity or equivalence of knowledge, qualitative
studies of lay epidemiology and lay accounts of the aetiology of ill-health are of potential value to the discipline. Paying attention to the ways in which professional and lay epidemiology converge and diverge offers possibilities for more effective and more radical health education based on both the public understanding of science and a more scientific understanding of the public, and has the potential to unveil theories for pathways to ill-health based on more complex interactions of exposures. Perhaps a more public exposure of Rose's sophisticated, succinct and far-sighted paper on the implications of various preventive strategies is just what is needed to stem a growing mistrust of science and health education in the public at large.

References