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Citation:

ALLMARK, P. J. and TOD, A. (2006). How should public health professionals engage with lay epidemiology? *Journal of medical ethics*, 32 (8), 460-463. [Article]

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Conflict of interest: See statement at end of manuscript.

Key words: Lay epidemiology; epidemiology; public health; ethics.

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How should public health professionals engage with lay epidemiology?

Abstract

“Lay epidemiology” is a term used to describe the processes through which lay individuals understand and interpret health risks. It is seen as a barrier to public health when the public disbelieves or fails to act upon public health messages. We propose that there are two elements to lay epidemiology: i) empirical beliefs about the nature of illness and ii) values about the place of health and risks to health in a good life. Effective public health must engage with both elements. Such engagement would involve attempting to change the public’s empirical beliefs and values. This is of concern, particularly in a context in which the lay voice is increasingly respected. However, we argue that, empirically, the lay voice should defer to the scientific voice of standard epidemiology provided there is a clear distinction between the measurement of risk, which is empirical, and its weighting, which is based on values. On values, we suggest that almost all people view health as an important value. Furthermore, people do discuss and reflect on their values. Public health professionals are, therefore, entitled, indeed advised, to take part in that process. In the final section we defend this view against some potential criticisms.

Abstract word count: 199

Key words: Lay epidemiology; epidemiology; public health; ethics.

Full word count: 3286 (ex. References), 3929 (incl. References).

How should public health professionals engage with lay epidemiology?

Introduction

This paper presents a new interpretation of, and reflection on, a theory that has been widely used in the discussion and development of public health policy. “Lay epidemiology” is a term used to describe the processes through which lay individuals understand and interpret health risks. In doing this they use numerous empirical sources, such as the observation of cases known to them, newspaper reports and television dramas. Lay epidemiology is seen as a barrier to public health in at least two ways. First, people don’t always believe health messages issued from public health bodies. Second, people have cultural or individual values that undermine health messages: for example, health-threatening activities are viewed as “naughty but nice”. To be effective, therefore, public health professionals must engage with lay epidemiology. However, for various reasons one might question the right of public health professionals to challenge the beliefs and values of individuals and communities. In this article we defend the idea that public health professionals should engage with lay epidemiology. We begin by tracing the emergence and development of the concept.

The emergence of lay epidemiology

The phrase “lay epidemiology” was coined in 1991¹ in an article that described the health beliefs and attitudes found in ethnographic research performed in South Wales. The authors have since published several papers in which the concept is used^{2 3 4 5 6} and a number of other writers have taken it up.^{7 8 9 10 11} In these articles at least two distinct elements seem to make up lay epidemiology. The first is empirical: lay beliefs about the causes, course and management of illness. The second is values: lay beliefs about the place of health and risks to health in a good life. In almost all the

articles, lay epidemiology is seen as oppositional to public health in one or both of these elements. However, the articles differ in the way they view this opposition. Let us take each element in turn, starting with the empirical.

Empirical element

The originators of the term emphasise the veridical strength of the empirical beliefs in lay epidemiology in opposition to public health propaganda. At the heart of their position is concern about the prevention paradox in public health first identified by Rose.¹² The paradox is that targeting the behaviour of the large majority of the population that are at medium or low risk of a particular illness related to a behaviour is effective at population level but has little effect at individual level. For example, an individual whose dietary fat intake is about average is unlikely to gain from reducing it further; nonetheless, were the whole population to reduce their dietary fat intake this would have far greater effects on the level of coronary heart disease (CHD) than would simply targeting those whose dietary fat intake is particularly high. As a result, Davison *et al*¹ say public health professionals have opted for “worthy dishonesty” (p.16): simple and untrue messages that exaggerate the risks of particular behaviour and the benefits of changing that behaviour.

The problem with such dishonesty, aside from its ethics, is that lay epidemiology has cottoned on to the prevention paradox in at least two ways. First, the lay public see the “unwarranted survivals” and “anomalous deaths” that run contrary to public health messages.¹³ Second, they note the rarity of conditions that are associated by public health with common practices, for example, as malignant melanoma is associated with sun-tanning.¹⁴ Furthermore, the lay public has become aware of the fickleness of health messages: for example, alcohol is damned and praised almost simultaneously for its

health effects.¹⁵ As a result, lay epidemiology rightfully “smells a rat” with public health messages.

In contrast to this “pro-lay epidemiology” view, others say the task of public health professionals is to use information from standard epidemiology to correct the lay public’s misapprehensions.^{8 13 16} The hope is that this correction will lead the public to behave in accord with public health messages. However, people’s behaviour is a product not just of their empirical beliefs, their values are also central. Someone will not give up smoking simply because he believes it injurious to his health, he must also believe that this risk of injury outweighs the pleasure of smoking. This takes us to the second element.

Values

When weighing up the potential benefits of public health measures, public health professionals view the outcomes for population health as of primary importance.¹⁷ If a change in population behaviour would result in a reduction in population illness then it is desirable. In contrast, the lay public takes an “all things considered” view. As a result there are subtle differences in the way behaviour that is deemed bad for the health might be seen. At least three categories of “bad” health behaviour may be discerned.^{18 2}

- i) Bad because poisonous. Such behaviour damages health and has little or no obvious pay-off. Eating foods that contain toxins, such as salmonella, is an example.
- ii) Bad but desirable. Whilst damaging to health, smoking, alcohol, illicit drugs, fatty diets and indolence all have rewards that may outweigh any health benefits gained from avoiding them.
- iii) Bad in some ways, good in others. As an example, some research suggests that people view the health risks of

smoking as outweighed by its health benefits such as reduction of stress.¹⁹

The public is likely to respond positively to messages about poisonous behaviour. Their attitude to messages about the other two types will be more ambiguous. Thus, the all things considered view of lay epidemiology might conflict with the health-oriented view of public health professionals.

This conflict is seen in the role of culture in lay epidemiology. In taking an all things considered view, individuals will be affected by culture in at least two ways:

- i) Some cultures will place a high value on attitudes or activities oppositional to public health. *Tod et al*^{20 21} examined barriers to the uptake of services for CHD in a South Yorkshire working class community. These barriers included the cultural value placed upon independence, strength and self-sufficiency. People put up with symptoms of CHD rather than be branded ill and in need of medical help.
- ii) Much of the public health message is conveyed in terms of risk. However, cultural values will affect how people weigh up behaviour as risky or not. If circumstances outside of one's control are such that life expectancy (in terms of morbidity and mortality) is low then this will reduce the import of additional risk. For example, if one is likely to die or be miserably ill by the age of 50²² then smoking will not be seen as likely to rob one of much useful life. Similarly, anti-smoking messages will fail in those deprived communities where smoking may have a high value in an otherwise miserable existence.⁶

We are now in a position to set out the problem that lay epidemiology presents for public health.

The problem for public health

Effective public health measures will *inter alia* require engagement with lay epidemiology. However, there are reasons to be uneasy about doing so, both in terms of empirical beliefs and values. Again, we shall take these in turn.

We have seen the claim that lay epidemiology “smells a rat” in public health advice. In that this suggests that lay epidemiology is empirically correct there is no question that public health professionals should not seek to challenge it. Furthermore, we noted above that values play an important role in our decisions about whether something is of high or low risk. Epidemiologists cannot simply say that, for example, smoking is highly risky to health. Smith²³ [p. 498) takes this further:

“This is the way the world is going. It’s called postmodernism. There is no ‘truth’ defined by experts. Rather there are many opinions based on very different views and theories of the world.”

Medical knowledge is no longer privileged; rather it is one opinion to be weighed amongst others.¹⁶ Indeed, the real experts are those with the illnesses. In this climate any attempt by public health professionals to correct lay views looks unjustified.

Ex fortiori how can we justify challenging people’s values if we cannot even justify challenging their empirical beliefs? Indeed, given that the difference in values between people often reflects cultural differences it would be disrespectful to attempt any such change.

Thus one might argue that public health professionals should attempt to change neither the empirical beliefs nor the values inherent in lay epidemiology. How might public health professionals respond to this argument?

Engaging with lay epidemiology's empirical beliefs

The term "lay epidemiology" invites a post-modern interpretation. One is tempted to compare it directly with standard epidemiology (henceforth simply "epidemiology"). The thought is that epidemiology is at the root of the public health view of health and risk whilst lay epidemiology is at the root of the lay view. Lay epidemiology is, on this account, different but equal to epidemiology.

However, it is worth noting in the first place that lay epidemiology involves the complete set of empirical beliefs and values relating to people's behaviour concerning, and attitudes towards, risk. By contrast, epidemiology is purely empirical, the study of the occurrence and spread of illness in the population. As such they are not directly comparable. Furthermore, those who coined the term "lay epidemiology" had no post-modern intent. Their observation was that whilst the lay public gathered empirical beliefs about health risk in a piecemeal way, many of these beliefs matched those in epidemiology and contrasted with the messages given by public health bodies. Hence the term "lay epidemiology" was used to emphasise the correlation of lay and professional beliefs, not their opposition. The opposition is between both types of epidemiology and public health messages that are seen as simplistic or even untrue. Used in this way "lay epidemiology" is at odds with a post-modern view because it relies on the idea of truth that post-modernism eschews.

If this is accepted there is no reason to expect lay epidemiology to be better than epidemiology at discovering empirical facts. Epidemiology

employs systematic research; lay epidemiology employs partial and piecemeal techniques. As noted above, lay epidemiology will err. Of course, epidemiology itself may err. This is shown particularly when observational epidemiological studies report findings that are subsequently not replicated in randomised controlled trials.²⁴ Nonetheless, epidemiology is less likely to err and more likely to correct its own errors. This gives purchase to the idea that lay epidemiology can stand in need of correction in its empirical beliefs.

What, though, of the concern that risk-related terms used in epidemiology are not straightforwardly empirical because our values determine, for example, what we perceive to be a high risk? Here we should avoid being distracted by the way in which probability facts can be presented in a number of different ways.²⁵ All such presentations refer to the same fact; as such, this point does not support the concern. Nor should we be distracted by disputes in probability theory between, for example, Bayesians and Frequentists. Whilst their disputes are important, neither account is consistent with a post-modern view.

There remains one serious argument in support of the idea that risk-related terms are not truly empirical. This is that our perception of risk depends on our circumstances and values. This argument can be tackled by drawing a distinction between the measurement and the weighting of risk; in other words, one can distinguish between the precise level of risk and whether it is worth worrying about or acting upon. In measurement terms there are ways of presenting risk in a fairly precise way. Many of us are familiar with taxonomies of risk presented in drug information sheets listing side effects. In weighting terms, though, whether a risk is worth acting upon will be strongly dependent upon values. Therefore, public health information could describe some behaviour as high risk and define this precisely provided no weighting conclusions are drawn from this.

We conclude, therefore, that a proper account of lay epidemiology gives no support to the idea that it represents an alternative to epidemiology; neither does it support a post-modern account of truth in medicine. As such, there is no problem in principle with the idea that public health professionals can challenge lay epidemiology on empirical grounds. Furthermore, it is possible for public health professionals to present epidemiological facts in ways that are true and meaningful. What, though, of the task of challenging the values inherent in lay epidemiology?

Engaging with lay epidemiology's values

To put this question another way, what should public health bodies do if the public, once informed of an avoidable health risk, chooses not to avoid it? One response is to say they should do nothing further; the job of public health professionals is to inform the public, how they respond is their business. We shall call this a libertarian response. It has *prima facie* plausibility. However, equally plausible is the contradictory view that one should sometimes challenge the values and attitudes of individuals and communities that leave them vulnerable to avoidable illness. To take a simple example, it seems right to challenge the suicidal behaviour of a young person determined on self-destruction following disappointment in love. Here we shall develop this idea further.

In this context, values are the views people hold about what is worthwhile to do or to have in a good life. Some of these will be instrumentally worthwhile, such as money, others intrinsically, such as independence or friendship. Some will be temporary, such as a brief infatuation with Sudoku, others fairly permanent, such as love of family. And all will be weighted as worthwhile to a greater or lesser degree. Values will originate from a mixture of culture, personality, experience and reflection. We have seen already that some working

class communities in South Yorkshire place high value on strength and independence.²⁶

It is tempting to believe there is no way of judging values and that it is wrong to do so; different individuals and cultures have different views on what is worthwhile and that's that; values are inaccessible to reason. This belief lies at the heart of libertarianism. However, at least two considerations suggest it is flawed.

The first is that values and empirical beliefs interact. If one believes there is little one can do to improve the course of one's life then one may be more inclined to value immediate over deferred pleasure. Changing the empirical belief may change the value in such cases. The second is that some values seem widely shared. One such is health: for almost all people, other things being equal, it is better not to be ill. Such widely shared values enable us to have meaningful reflection on what constitutes a good life both within and between individuals. Thus someone might decide he is spending too much time on Sudoku or work and too little with his family, or that he really should lose some weight. Similarly, close friends might suggest this to him in the hope he will see reason.

Hence one may accept that people take an all things considered view of what makes certain behaviour worthwhile without necessarily accepting that public health professionals should not engage with the value-based element underlying such behaviour. Because health is an important and widely shared value, public health professionals are entitled to note where people are making sub-optimal health decisions and encourage reflection and change. This view might be challenged for at least three reasons.

- 1) *The role of the State.* Anyone sympathetic to a libertarian view is likely to find it unacceptable for the State to interfere with the

values of its citizens; people should make their own decisions and live (and die) by them. However, many States are involved in the provision of health care in a way that is inconsistent with this view. If a State provides health care then this weakens individual choice, particularly that concerning whether one should make one's own provision. But if such State provision is acceptable there seems no reason in principle why the State might not also be involved in endeavouring to maintain the health of citizens.

- 2) *The prevention paradox.* We discussed above the argument that the prevention paradox lay at the heart of the “worthy dishonesty” adopted by public health bodies to which lay epidemiology cottoned on. The implication is that if the public were properly informed about public health injunctions they would decide not to follow them: for example, from the all things considered perspective taken by lay epidemiology it might not seem worthwhile to reduce one's fat intake if it offers little chance of personal benefit. Davison *et al*¹ suggest that this implication is based on the assumption that individuals will only change their behaviour if they anticipate personal benefit, an assumption they question. It might be that people would be willing to make behaviour changes for the sake of others, such as family or community, rather than themselves. The individual's belief here might be, say, that he feels that any personal gain is unlikely and certainly not worth the self-sacrifice involved; however, he might be willing to make that sacrifice for the sake of his children. Nonetheless, if public health bodies are unable to persuade people that such changes are worthwhile then that should be an end of it. In practice though, as we have suggested, people's values are changeable and open to reasoned discussion. Public health bodies are

entitled to take part in that discussion. There is, however, no justification for “worthy dishonesty” even if it were effective.

- 3) *Cultural intolerance.* We saw earlier that some communities might have values that run counter to public health aims. The emphasis on strength and independence in one community was part of its resistance to the use of services for CHD and resulted in avoidable illness.²⁷ Clearly here it would seem undesirable to undermine such values simply in order to promote health. Part of the concern is that attempting to change cultural values to accord with the aims of public health represents cultural intolerance, a desire to homogenise people so they are similar to the currently small number of largely middle class people who are actively health seeking.²⁸ However, the very existence of lay epidemiology might suggest we should not be too worried about this. For example, despite years of public health information about smoking, the most deprived communities have remained immune to the messages.⁶ The message that public health professionals need to take from this is that it needs to be aware of the different cultural contexts in which it operates. In the South Yorkshire communities it must be aware provide services in a way that complements the values of that community.²⁹

Conclusion

Lay epidemiology is an apparent problem for public health professionals, as it seems to contain a countervailing set of beliefs and values. However, its very existence shows that health is of concern to most people. Furthermore, *pace* postmodernism, most people will want to know and act upon empirical beliefs about health that are true. Epidemiology is far more effective at finding these than is lay epidemiology. As such, public health professionals are right to present its findings to the lay public in ways that are meaningful.

Lay epidemiology

We have also argued that people's values are open to rational discussion and that public health professionals are right to take part in this; but they must be honest. They should also be aware of the cultural contexts that mean, for example, that something high risk and worth avoiding for one person is not the same for another. Engaging with lay epidemiology is likely to increase the effectiveness of public health work, as well as helping ensure it is ethically sound.

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Competing interest statement: All authors declare that the answer to the questions on your competing interest form bmj.com/cgi/content/full/317/7154/291/DC1 are all No and therefore have nothing to declare.